

End Notes

4th December 2018: In the footsteps of Peter Noll

Browsing the shelves of a second-hand bookshop in Galway some months ago, I came across an old paperback entitled '*In The Face of Death*'¹ by Peter Noll. Noll was a Swiss academic lawyer who died in October 1982 aged 55. Ten months earlier he had been diagnosed with cancer of the kidney. His urologist had informed him that with surgery followed by radiotherapy, his survival chances would be good (c. 50%) but that there was a possibility that he might have to wear a colostomy bag;² secondly, that sexual intercourse would no longer be possible as he would no longer be capable of having an erection. He was assured that there would be few other limitations, hiking in the mountains and skiing – a favourite pastime for Noll – would still be possible.

Noll said that he would never, under any conditions, consent to such an operation. The surgeon replied that though he had respect for such a position, Noll should get as much information as possible from other doctors as well.

Outlining his objections to a lawyer friend and colleague who was also a medical doctor; Noll explained:

*I don't want to get caught in the surgical-urological-radiological machine because then I'd lose my freedom piecemeal, my will will be broken as hope diminishes, and I'll wind up one way or the other in the well-known death room that everyone skirts. Anteroom to the cemetery*³.

The friend's initial response was that Noll was crazy to refuse life-sustaining treatment, though later he began to have some sympathy with Noll's perspective.

¹ Noll, Peter. *In the Face of Death*. [Trans. Hans Noll]. New York: Penguin. 1989.

² A colostomy bag is a receptacle affixed outside the body into which urine drains and which requires regular emptying.

³ At p.5.

Noll was not especially religious - he was more spiritual than religious and more theist or agnostic than atheist.⁴ He found his solace elsewhere: "*Only music is abstract enough to express the transcendental.*"⁵

Diagnosed with cancer and having refused treatment, he decided to keep a journal of his voyage into the foothills of his death. He began his diary on 28th December 1981. His final entry was 10 months later on 30th September; his daughter wrote an epilogue telling of his last days until his death on 9th October 1982.

One of the first entries of his journal was headed "*Marrakech, January 3 1982*" I felt I had met a kindred spirit not only because this indicated a love of travel which I also shared and a common background in law but because I too had been diagnosed with terminal cancer and had also refused the standard treatments: the surgery, the radiotherapy and the hormone therapy. He, however, was 55 whereas I was 73.

I bought Noll's book and read it with the same eagerness, care and respect of one who hoping to scale a mountain, would read the diaries of earlier climbers who had succeed. 'Success' may seem a strange word to use in such circumstances but I use it as describing not the reaching of the summit - death - for that inevitably comes to us all, but rather the journey itself and whether or not it can be accomplished with some degree of serenity, peace and acceptance.

Nearly 40 years ago my father, Frank, died of lung cancer and in hospital although wishing to die at home. Morphine - though relieving his pain - caused him such mental anguish that he resolved to face his death in full consciousness. Then, though I not only loved but deeply liked my father who was a kind and generous man, courage would not have been a virtue that I would have readily ascribed to him but I found the fortitude and courage in the manner in how he faced his own death, deeply admirable; but now even more

⁴ P.48:

"I shall always admit that the idea of an eternal kingdom of God, whether I experience it or not, is one that continues to overwhelm me...."

⁵ P.41

so and in a much more personal sense. I now thank him for the example that he set before me.

In opening Noll's book, my attitude was akin to that of a sailor heading alone onto uncharted waters whose rough charts carried the fearsome admonition "*Here be dragons.*" Reading it helped settle my mind and lessen my fears.

Months later, Noll's book was brought sharply back to mind on encountering a chance quotation:

"When things become truly difficult and unbearable, we find ourselves in a place already very close to its transformation."

The quotation was from a recently published book⁶ of letters written by the poet Rilke to friends of his who had recently suffered a loss. In the Preface, the editor emphasises that these were letters of condolence not of consolation – a full acknowledgement and acceptance of pain rather than a bland assurance *'that all will be well'*. To Rilke it was important to have an *"unflinching acknowledgement of death"* because in that – rather than in its denial⁷ – lay the means of personal transformation and growth. This brought to mind my reading a book by Rilke many years earlier in which death also took centre stage. It was *'The Notebooks of Malte Laurids Brigge'* and it would be trite to say it made a deep impression on me – it actually shocked me out of my complacency and out of the 'common-sense' view that death was not an appropriate subject for 'polite' conversation and that to insist on discussing it was to evince 'unhealthy' preoccupations.

I still treasure my original copy in which I had inscribed the date: 1988. That was the year that my wife Mette and I had just separated and I had completed the restoration of an old barn where I would live and where I also intended to have my workshop (having jettisoned a career lecturing in mathematics, I had become fascinated with sculpture and wood turning in which I had begun to have some considerable success).

⁶ Rilke, Rainer Maria. *The Dark Interval. Letters on Loss, Grief, and Transformation.* (Trans. Ulrich Baer). New York: Modern Library. 2018.

⁷ An extreme example of such denial are groups who believe that it is possible to live forever. ... "*The deathist paradigm has to go ... It's time to look beyond the past of dying to a future of unlimited living.*"
<https://www.theguardian.com/global/2019/jun/23/how-to-live-forever-meet-the-extreme-life-extensionists-immortal-science>

I was then in my early forties and intellectually and emotionally somewhat adrift and a few months travel to an exotic destination appeared to offer the possibility of getting some perspective on my life - a pattern that I was to follow every couple of years and still plan to do: barely three months ago I travelled to Iran to visit the mosques and bazaars of Shiraz, Esfahan and Yazd which I had first visited nearly twenty years earlier. The kindness and hospitality of the Iranian people was then - and is still even in such turbulent political times - a testament to the depth of their cultural heritage.

Tibet seemed a sufficiently 'awkward' destination to aspire to and I booked a place on a small tour from Nepal - then the only way to obtain a Tibetan visa. Afterwards I planned to travel alone to India.

Of my many impressions of Tibet, one especially astounded me: the lively bright smiling eyes of the Buddhist monks⁸ that I encountered whose demeanour contrasted so greatly with that of the Catholic priests in the Ireland of my youth. Before travelling to Tibet I had considered myself an avowed atheist - as I still am - but then without any interest in spiritual matters and without any knowledge of Buddhism. On my return to Ireland, however, I found that a taste of Buddhism had lingered and my appetite had been whetted; I began a study of Zen and in the years since, have followed a discipline of daily meditation.

On leaving Tibet I began my independent travel and my first stop was Varanasi which was on first impressions, an assault on the senses but not in an threatening way; on the contrary, I surprised myself by noting how at home I felt amongst all the crowds. In Varanasi, I visited the ghats and saw where the bodies of the dead were cremated before the remains were proffered to the sacred Ganges. Later I travelled north to Dharamsala (where the Dalai Lama had sought sanctuary having fled Tibet) and one evening as I browsed a market stall, I found a human thigh bone from which a craftsman had fashioned a flute.

⁸ Years later I travelled to Ethiopia where the demeanour of the priests that I encountered provided a deep contrast to that of the Tibetan monks. The greed and voraciousness of the Ethiopian priests at the underground churches of Lalibela, was such that I began to imagine that they had dollar signs - rather than pupils - in their eyes.

Only now, some thirty years later, do I see how such encounters with, and such attitudes to, death which were so utterly different from my earlier understandings, might in 1997, have prompted me to begin postgraduate research in the Philosophy Department of UCC, on the ethics of the withdrawal of life-sustaining treatment from vegetative state patients.⁹

A central concern in writing that thesis was to argue that the attitude to death then prevailing in academic philosophy and medical ethics (*i.e* that death was an 'evil' to be fought by all means possible) was deeply misplaced. To me, death was an intrinsic part of the gift of life and was the framework within which a life must be lived and though the term 'evil' may be used in relation to actions *within* a life it has no applicability to the framework itself; to assert otherwise is a remnant of a biblical worldview. Accepting my view allowed one to speak meaningfully of '*a good death*'.

During my research I was surprised to see the prevalence of ideas of '*denial of death*' both in society generally and also within the medicine.¹⁰ A Pulitzer Prize-winning book by the psychologist Ernest Becker¹¹ was one of the most enlightening and personally transformative books that I have ever read.

The fruit of this reading was for me the realisation that the full acceptance of one's own mortality was the very salt of life: realising that one's time is limited, adds urgency to the task of separating the important goals of one's life from the trivial. Without such an attitude then: *Why do today what one can postpone till tomorrow?*

The personal philosophy that I have evolved is that being confronted with a difficult choice of life paths, to imagine reviewing my life on my deathbed and

⁹ An MPhil thesis entitled '*An alternative conceptual structure for the resolution of 'end-of-life' problems involving PVS patients*'. It is available online at gerryroche.com and academia.edu

¹⁰ The testimony of the archivist Catriona Crowe on the death of her partner, provides a recent harrowing example:

... He was brought into the critical care part of the facility, an unpleasant corridor off the main A&E. Even though I explained his heart was badly damaged, no cardiologist saw him until he was dying three hours later."... .. and after he died she felt that "everyone fled" as she was taken to see him. "No one stayed near me. It was as if the staff were ashamed of their failure to save him."...

Eilish O'Regan 'Porters joked as they wheeled my dead partner away' *Irish Independent*, 20th May 2010.

¹¹ Becker, Ernest. *The Denial of Death*. New York: The Free Press. 1973.

posing the question: *Would I then be proud that I had made this particular choice even if it had not succeeded? Proud that I had opted for the less-easy, less common-sense, path?*

I had found Peter Noll's book extremely helpful in attempting to confront and accept my own terminal illness; doubtlessly his book had helped many others and had been of great assistance to Noll himself as a method of personal discipline and reflection.

I decided to attempt to emulate Noll's example as best I might.

8th December 2018: My encounter with cancer

In summer 2010, a PhD dissertation¹² on which I had been working for over seven years was – as I thought – within weeks of completion and I had planned a celebratory trip: overland to Syria, then by cargo boat to Alexandria then back to Venice by boat.

However as in the best laid plans of mice and men, complications arose in the form of an objection from my PhD supervisor ostensibly because my dissertation considerably exceeded the maximum stipulated word-count. As was to transpire later¹³ these objections were grounded in what can only be described as 'religious' in nature and occasioned by my use of a stipulative definition¹⁴ of personhood. This necessitated the appointment of a new supervisor and a delay in the submission of my dissertation. I decided to travel nonetheless – the '*Road to Damascus*' had fascinated me since childhood, to forsake it now would be unforgivable.

Days before my departure, I received an email from John Walsh – a friend since student days in UCD. He had qualified in medicine and practiced in the US. We had kept in contact and, some years earlier, he had told me of his being diagnosed with prostate cancer. Having had surgery and radiotherapy which had been unsuccessful, he had just begun hormone therapy which, he said, was the most enervating of all. As he wrote from a New York hospice:

¹² Gerry Roche. '*A philosophical investigation into coercive psychiatric practices*'. 2 volumes. It is available online at gerryroche.com; academia.edu and criticalpsychiatry.co.uk/

¹³ A draft email was mistakenly sent to me by my supervisor which was followed within minutes by an attempted retraction. The word-count of the thesis as finally submitted and accepted, exceeded that of the draft as originally submitted.

¹⁴ Whereby necessary and sufficient conditions were specified for the ascription of personhood.

... the inexorable progress of my disease and it's attendant unpleasantness's has jerked the focus and thinking of all my care-givers into the reality that their efforts are to be best spent on well planned palliative care and provision of comfort rather than the common puritan worries regarding drug abuse often while whistling past the graveyard. Already the benefits of this change are evident and I am more comfortable.

Sadly, less than a fortnight later, he died but by then my travels were underway. John, being a man of independent mind and one unlikely to be unduly swayed by the views of others, led me to wonder why the decision to focus on palliative care had been made by his care-givers rather than by he himself – a reflection which brings to mind Noll's fear of becoming entrapped in a medical juggernaut where "*... I'd lose my freedom piecemeal, my will will be broken as hope diminishes, ...*"¹⁵

Returning to Ireland some months later I became immersed in the redrafting of my dissertation having been assured that it would now proceed without objection.

Shortly after my return, I visited my GP for a routine check-up which included a PSA test. On receiving the test results, he suggested that it would be wise to have a biopsy to determine if cancer was present in my prostate. An appointment was arranged with a consultant at the Bon Secours Hospital in Galway, so that the biopsy might be taken. Arriving for the early morning appointment, the biopsy was performed and I was given medication to take both that night and the following morning to counter any possible infection; no other warnings or instructions were provided. Relieved that no problem had arisen, I relaxed, strolled into Galway for lunch and later drove home. That night still feeling no after effects of the procedure, I took the medication as instructed and went to bed.

A very troubled sleep ensued during which I began to feel extremely cold. Thinking that this was perhaps a reoccurrence of the malaria that I contracted in India some years before; I pulled on another duvet and hoped that time might bring some improvement.

¹⁵ *Supra.*

By morning the situation had deteriorated; I was extremely weak and losing my balance. I still remember attempting to open the cabin where I did my research; I had to use both hands to try and put the key in the lock. I went back to bed but that did not help; I tried to phone my GP but he was at lunch. Being alone in the house and realising that this was not a re-occurrence of malaria, I contacted the hospital and requested that the consultant who had carried out the biopsy, phone me back. He did and suggested that I go to the A&E at Galway University Hospital.

In view of the widespread reports of overcrowding at that A&E and the fact that he had not suggested that my medical history would be forwarded in advance nor that the name of a contact person would be provided, I believed his response to be cavalier especially as he had carried out the procedure and was now disowning responsibility for problems that ensued. My illness turned to anger - I refused to go to the A&E and said that I would head to the Bon Secours Hospital where I expected to be treated.

Meanwhile by chance, a neighbour had visited and - startled by my unsteadiness and appearance (I had a jaundiced pallor) - he contacted my GP who called to my house and on seeing me, decided that I required hospitalisation. He offered to drive me to the Bon Secours Hospital where, on arrival, I was admitted.

It transpired that I had sepsis with a temperature of over 104°F.

I had excellent care and remained in hospital for over a week but during my stay I had suggested to the Director of Nursing - who thought it an excellent idea - that a protocol be put in place especially for patients who were living alone, that they should be contacted the morning after a biopsy procedure to ensure that all was well and that, if not, and if necessary that the patient attend Galway University Hospital, that the medical history be sent in advance to a named contact person at the hospital. She had formally lodged a report of my experience as an 'Adverse Event' and informed me that the Hospital Administrator wished to speak with me before I left.

Even though I emphasised that I had no intention of taking legal action, his response to my suggestion was dismissive. To him, the consultant and the

hospital had acted at all times correctly and no change in procedure was required. I understood that to him, even the acknowledgment that procedures might be improved would possibly be a potential admission of liability and – unlike the Director of Nursing whose prime concerns had been patient safety, his were the deflection from the hospital, of any legal liability for negligence.

Some weeks later I had a phone call from the consultant who had performed the biopsy. I explained that I had no wish to commence any legal proceedings but that my interest lay solely in ensuring a change of protocol especially for those living alone. The conversation was somewhat stilted and that, along with a repeated clicking on the phone line, lead me to believe that the conversation was being taped and that the purpose of his call - like the Hospital Administrator - was purely defensive.

It was sobering to realise that the attempt to determine whether I had cancer, could, by itself, have proved to be the cause of my death, and that the chance visit of a neighbour, had saved my life.

The biopsy was positive for the presence of cancer.

10th December 2018: The diagnosis and the menu

Whilst in hospital I had met the urologist who had been unfailingly kind and courteous; later in his consulting rooms, he outlined the diagnosis and the possible treatment options. The biopsies had shown that cancer was present in 4 of the 6 sample biopsies to a level of Gleason 7; he recommended surgery (radical prostatectomy) as being the '*gold standard*' though with incontinence and impotence as possible side effects. As a less invasive treatment, he suggested the implantation of a radioactive seed or pellet (brachytherapy) which would be more convenient than external radiation.

I hesitated. The research that I had conducted for my PhD had left me deeply sceptical of medical 'certainties' and 'gold standards'; I had seen how supposedly authoritative studies - even those published in the most prestigious medical journals - were often compromised by the financial and other interests of the researchers and of the pharmaceutical industry. The financial ties were often hidden and sometimes resulted in the non-publication – indeed the

suppressions - of studies which conflicted with those interests. I decided to read more widely before making any final decision as to possible treatment. Browsing on the internet, I encountered numerous links to laser surgery which appeared then to be the most favoured in the UK and whose main advantage was its precision. Laser treatment was not at that stage available in Ireland and in discussing it with my urologist, he told me of a Galway patient who had had this surgery in London but returned home doubly incontinent. I wondered to myself whether had laser treatment been available in Ireland, it would have received such a damning indictment. One cannot ignore the fact that medicine is a business and even the most ethically responsible and conscientious doctor, cannot help but being swayed – even unconsciously – by financial considerations. In writing my PhD, I had encountered a study which noted that though physicians adamantly denied that receiving free lunches, subsidized trips, or other gifts from pharmaceutical companies has any effect on their practices, yet US pharmaceutical companies spent \$19 billion each year on such practices.¹⁶ Clearly the pharmaceutical companies had good reason to believe in the effectiveness of such 'inducements'.

I resolved to continue my reading and research.

My urologist had urged me to continue regular PSA testing with my GP and this I did for some time but I noticed that with each oncoming test, I began to be anxious as to what the result might be and - as these tests were performed each couple of months – I requested my GP not to inform me of the results but to keep them on file so that if necessary they could be reviewed at a later stage – a procedure not as 'head-in-the sand' as it might initially appear because the value of PSA testing is not in the individual results but rather in their sustained direction of travel.

Over the next months I came across a number of academic studies which deeply influenced my decision in relation to treatment. The first was a

¹⁶ Campbell, E. (2007). 'Doctors and Drug Companies — Scrutinizing Influential Relationships.' *New England Journal of Medicine*. 357:1796-1797.

Swedish study from 2008¹⁷ which compared surgery to 'watchful waiting'.¹⁸ The latter is a way of monitoring prostate cancer that isn't causing any symptoms or problems and postponing the consideration of treatment until problems attributable to the cancer, occur. In 1999 the study randomly assigned men to surgery (n=347) and to watchful waiting (n=348). After c. 10 years follow-up, 137 in the surgery group and 156 in the watchful waiting group had died; 47 of the surgery group had died of prostate cancer as had 68 of the watchful waiting group. In summary, 39% of the surgery group had died and of these prostate cancer had been the cause of death in 34% of cases; the corresponding figures for watchful waiting were 45% and 44%. Expressed somewhat differently: after 10 years, 14% of those who had surgery had died of prostate cancer in contrast to 20% of those in the watchful waiting group. Surgery when seen solely through the lens of increased life-span, was superior but when the poorer quality life associated with surgery (risk of incontinence and impotence) were considered then for me the balance changed and I decided to decline surgery.

Two years after my original cancer diagnosis an especially authoritative study¹⁹ – the so-called PIVOT²⁰ study – was published. Its objective was to determine whether surgery was superior to the palliative care of symptoms if and when they occurred. It concluded:

Existing evidence does not demonstrate the superiority of this procedure²¹ compared to expectant management ... The only randomised trial was limited by a small sample size but the results favoured expectant management. Radical prostatectomy provides potentially curative removal of the cancer. However, it subjects patients to the morbidity and mortality of the surgery and may be neither necessary nor effective.

The reporting of the results by the health correspondent of the *London Independent* was more forthright:

¹⁷ Bill-Axelsson A. *et al* 'Radical prostatectomy versus watchful waiting in localized prostate cancer: the Scandinavian prostate cancer group-4 randomized trial.' *J Natl Cancer Inst.* 2008 Aug 20;100(16):1144-54.

¹⁸ Also called 'active surveillance'.

¹⁹ It had been funded by the US Department of Veterans Affairs.

²⁰ Wilt, J. *et al* 'Radical Prostatectomy versus Observation for Localized Prostate Cancer' *N Engl J Med* 2012; 367:203-213.

²¹ I.e. surgery.

The results show that surgery did not extend life. A leading British specialist, who asked not to be named, said: "The only rational response to these results is, when presented with a patient with prostate cancer, to do nothing."

... [it] showed that those who underwent the operation had less than a three per cent survival benefit compared with those who had no treatment, after being followed up for 12 years. The difference was not statistically significant and could have arisen by chance. When the findings were presented at a meeting of the European Association of Urology in Paris in February, attended by 11,000 (sic)²² specialists from around the world, they were greeted with a stunned silence.²³

The phrase 'stunned silence' decided me: no treatment and no more PSA tests.

A 2014 update of the Swedish study gave me added comfort in its note that:

"A large proportion of long-term survivors in the watchful-waiting group have not required any palliative treatment."²⁴

It also found that in the over 23 years of follow up, 58% of those in the surgery group had died (31% were due to prostate cancer) as compared to 71% in the watchful waiting group (40% were due to prostate cancer).

Furthermore it found that surgery needed to be performed on 8 men to prevent one death and rather poignantly, noted that one man's death was as a consequence of surgery.

Over the following years I noted how previous 'certainties' were relentlessly undermined:

- "... the task force concluded that such testing will help save the life of just one in 1,000 men ... for every man whose life is saved by PSA testing, another one will develop a dangerous blood clot, two will have heart attacks and 40 will become impotent or incontinent because of unnecessary treatment ... PSA testing has become 'big, big, money'..."²⁵

- "... the researchers writing in the ... Journal of the National Cancer Institute concluded that using PSA velocity for prostate cancer detection is

²² 11,000 was the figure mentioned in the newspaper report but, perhaps, is a misprint for a more likely 1,100.

²³ Laurance, J. 'Study raises doubts over treatment for prostate cancer. Experts shaken by verdict suggesting thousands of men go through painful treatment for nothing.' *The Independent*. 28th April 2012.

²⁴ Bill-Axelsson A. 'Radical prostatectomy or watchful waiting in early prostate cancer.' *N Engl J Med*. 2014 March 6;370(10):932-42.

²⁵ Vastag, B. 'Government task force discourages routine testing for prostate cancer'. *The Washington Post*. 21st May 2012.

ineffective, that it leads to unnecessary biopsies and that references to it should be removed from professional guidelines ...”²⁶

- “More than 100,000 American men who each year undergo ‘curative’ therapy for low-risk prostate cancer should consider delaying treatment until the disease gets worse and possibly put it off forever ... because there is no convincing evidence that surgery or radiation therapy increases survival and there is good evidence that these procedures worsen quality of life ...”²⁷

- “Thousands of men with prostate cancer will be advised to avoid immediate treatment in a significant rethink ... the advice issued today by The National Institute for Health and Care Excellence (NICE) is designed to tackle the gruelling side-effects of treatment. ... ‘There is a trade-off for every man faced with the decision between a small chance of benefit and a very significant probability of side effects.’ Professor Mark Baker, director of clinical practice at NICE said.”²⁸

My confidence in following my own intuitions, was vindicated.

12th December 2018:

In 2012, the troubling questions concerning my prostate cancer treatment having been put to one side, my attention was again focussed on the upcoming viva examination for my PhD, in which I succeeded. The external examiner was Professor Vandenberghe of the University of Leuven who suggested that I publish the dissertation in book form and offered to write the preface. As the final dissertation was over 500 pages in length, this would have required considerable reediting and I decided to simply place the dissertation online as then the full text would be freely available to all.

After my conferring, one of my first steps was to send a copy of my dissertation to Professor Thomas Szasz whose writings I had long admired. Though himself a psychiatrist, he was a relentless critic of institutional psychiatry especially as regards its use of coercion. He had published over 30 books the most famous of which is *The Myth of Mental Illness* in which he argues that the term ‘mental illness’ should not be interpreted as an illness but rather as a metaphor for problems in living. I received a very encouraging reply which complemented me on the comprehensiveness of my research; a

²⁶ Bakalar, N. ‘Prostate guidelines causes many needless biopsies, study says’ *The New York Times*. 28th February 2011.

²⁷ Brown, D. ‘Many U.S. men with low-risk prostate cancer should delay or forgo treatment, panel says.’ *The Washington Post*. 8th December 2011.

²⁸ Smyth, C. ‘Men told to wait before prostate treatment’ *The Times*. 8th January 2014.

response which I especially treasure as he was then over 92 and died shortly after.

I also submitted the dissertation to the *Critical Psychiatry Network*²⁹ (an internet resource for psychiatrists) where within weeks, it ranked in the top 5% of papers. I also submitted it to *Academia.edu* which is the most widely used internet resource for academic papers and surprisingly, I was the first to generate the subject heading "coercive psychiatry". A Google search to-day for the tabs "philosophy, psychiatry, coercive" [with no mention of my name] list my dissertation among the first handful of results even though many hundreds of thousands of results are generated.

Looking back on my life from where I now stand, this dissertation is the accomplishment of which I am most proud. The fact that it required an almost twenty year period of gestation is to me, also a source of great wonder and pride.

The long circuitous route to my PhD began in a university bookshop in Cairo in 1995. I was at the end of what had been an ambitious trip overland from Nairobi to mark my 50th birthday. The book³⁰ that I had found was a collection of articles analysing the concept of rationality. Some days earlier I had visited the Egyptian Museum and seen a statue of the Pharaoh being blessed on one side, by Seth (the god of chaos) and on his other, by Horus (the god of order) and what I found especially fascinating, was that he was being blessed *equally* by both. Reflecting on this, I glimpsed its wisdom: that order, on its own, leads to a type of death or stasis and it is only with the introduction of a modicum of chaos that the seeds of creativity can emerge and bear fruit.

My first studies at university were in pure mathematics followed by postgraduate work in logic; the concept of proof in these disciplines is extremely rigorous: one may not progress past a line of a proof if it is possible to raise even a scintilla of doubt. 'Rationality' and 'common-sense'³¹ are often

²⁹ <http://www.criticalpsychiatry.co.uk/>

³⁰ Manktelow, K.I. & Over D.E. (Eds) *Rationality: Psychological & Philosophical Perspectives (International Library of Psychology)*. London: Routledge (1993).

³¹ David Papineau who is Professor of Philosophy of Science at King's College, lampooned this idea in an essay entitled 'The Tyranny of Common Sense.' [*The Philosophers Magazine* 2006]:

used in everyday discourse as having a similar property of indubitability but they do not: they are but a simulacrum providing just an ersatz version of logic though often clad in the raiments of rigor. It occurred to me that 'rationality' and its bed-fellow 'irrationality', would be an interesting field of study. Later I realised that an even more interesting area of study would be the use of the term 'irrationality' in psychiatry especially because psychiatry functioned on behalf of society not only as the 'official certifier' of irrationality but was also licensed to use the penalties of coercion for what it deemed to be, gross transgressions of the norms of rationality. Having had depression in my youth, a tentative brush with psychiatry had left me highly sceptical of its verities. As a first step, I applied to participate in a postgraduate conference in Southampton on the Philosophy of Psychiatry.

The main conference speaker was Professor Bill Fulford, a philosopher and a psychiatrist who held Chairs in both Oxford and Warwick Universities. He was author of the main textbook on the Philosophy of Psychiatry and was the most eminent authority in this field in the UK.

Fulford was a very engaging speaker and took 'delusions of infidelity' as the topic of his lecture in which his prime example was that of a man who believed his wife to be unfaithful but who was unable to justify this belief; to Fulford, this man was delusional and to Fulford, this 'diagnosis' necessitated involuntarily committal to a psychiatric hospital.

Fulford then added a gloss to his example: the interviewing psychiatrist had earlier been told by the man's wife that she had in fact, been unfaithful. To Fulford this changed nothing; his conclusion that involuntary committal to a psychiatric hospital was required, still stood.

To me this was manifest nonsense: man does not – indeed cannot – function as a type of proof machine scooping up premises, testing them, stringing them into syllogisms, bagging the conclusion and then heading ever onwards; ready at the slightest murmur of dissent to display all the steps which enabled him to

Any amount of nonsense was once part of common sense, and much nonsense no doubt still is. It was once absolutely obvious that the heavens revolve around the earth each day, that the heart is the seat of the soul, that without religion there can be no morality...

reach his present position. I gave the example of a schoolteacher who confides to her headmaster (who was independently aware of the truth of the allegation) her unshakeable belief - garnered from surreptitious glances, smiles and suchlike - that a colleague was having a sexual relationship with a pupil; given that she cannot justify the belief, I posed the question: *Is it conceivable that the headmaster could accuse this teacher not only of delusion but on that ground, render her liable to involuntary psychiatric detention?* I suggested that a more likely response from the headmaster would be a recognition that the teacher had been unusually perspicuous to notice what others, less observant, had not noticed.

Convinced that this concept of delusion rested on extremely tenuous intellectual foundations, I realised that I had found a research topic that had grabbed my attention and with which I could enthusiastically – and with luck, fruitfully - engage. Professor Fulford offered to accept me as his PhD student but it transpired that the yearly university fees in the UK would have exceeded Euro 12,000. Later, I was granted a three year Doctoral Scholarship by the University of Limerick the topic being an examination of the psychiatric usage of the term 'irrationality'. Throughout the following eight years of study, anytime my energy appeared to wane, the remembering of Professor Fulford's example of jealous husband, reenergised me and sent me forth with renewed enthusiasm.

14th December 2018: The lure of the Caucasus

Over the years I had become fascinated with Russia especially its literature, poetry and music and the vast unsulliedness of its nature especially in the East.

In the Spring of 2016, I had travelled to Siberia: to Novosibirsk, Tuva, Irkutsk and Lake Baikal. Travelling on my own with a backpack, I became more and more conscious of a loss of energy, occasional headaches and an impaired sense of balance. I consulted my urologist on my return and he requested an MRI scan.

Reviewing the scan he informed me that the cancer had spread from the prostate. Telling him of my love of travel, I voiced the hope that I would be

able to manage one more trip to Russia in the following Spring; a visit to the Caucasus was my goal. The Russian novelists Lermontov, Turgenev and Tolstoy had been fascinated with this region considering it a place apart; singular in its people and its mountains – the very epitome of a frontier land.

The urologist told me that I couldn't make any such trip – not in the sense that he believed it to be unwise but that I would not be physically able. From this response I gleaned that I had perhaps seven or eight months to live. That evening I booked a flight to Sochi for the following April. When I finally arrived at Dombay in heart of the Caucasus, I sent him a postcard not in any sense as a gesture of reproof but rather in celebration of unfettered optimism.

The magnificence of the Caucasus stunned me: on first glimpse they extended from horizon to horizon, an impenetrable barrier and appeared as massed serried ranks of cavalry, the white tops of their lances glistening in the sun with Mount Elbrus towering over all like a medieval warlord. Even if the journey might have harmed my health it replenished my spirit bountifully.

Buoyed by some sense of rebirth - even invincibility – I visited St. Petersburg that Christmas and then Iran the following August and there began my comeuppance.

16th December 2018: A pussy-cat or a tiger?

In discussing prostate cancer urologists and oncologists distinguish between pussy-cats and tigers, the latter being highly aggressive; the problem being that at the time of original diagnosis, there is no reliable method to distinguish between them. However, mine - if indeed it was a pussycat - was beginning to stretch its claws.

Arriving in Esfahan, I had booked into a small, inexpensive but comfortable hotel. The hotel lacked a lift and problems first began to occur in trying to descend the marble stairs which lacked handrails; once on level ground all was well but climbing – or even more so descending – posed great problems.

I had booked into the hotel for a week and then planned to spend a week in Yazd and a final week in Shiraz. Having booked a bus ticket to Yazd; packed and ready to go I had a final visit to the toilet. Instead of urine, there was a torrent of blood. I briefly considered seeking medical assistance but guessed

that my medical insurance would have resulted in me being flown back to Ireland. I decided to continue to Yazd as planned. Arriving at the bus station, I found that bus would lack any onboard toilet but I decided to press on even though it was a four hour journey. Arriving in Yazd, I found myself unable to descend from the bus and needed the support of a friendly shoulder.

'Toilet-wise' all began to return to usual over the next few days but I decided to take a taxi to Shiraz and then from there back to Esfahan for my return flight. Despite the distances involved being each c.450km the fare was about Euro25 – an eloquent indicator of the parlous state of the effect of US sanctions on the Iranian economy.

Despite the difficulties, visiting Iran again was a wonderful rich experience especially to spend time amongst such a gracious, hospitable and deeply cultured people.

I had absolutely no regrets, only joy at succeeding to complete the journey.

18th December 2018: The dénouement

Arriving back in Ireland, I stayed overnight in Dublin and the following day a friend gave me a lift home. I live alone in a stone house which I built when I first moved west to Clare. It is in the Burren and on the seashore – a place of solitude and wondrous beauty to which I always give thanks on my return. Each morning as I look on the wide expanse of sea and mountains I realise that I am truly blessed to have found such a haven – a heaven on earth.

Within an hour of my friend's departure, I was overcome with an extreme tiredness. I was no sooner in bed than I felt the urge to get up and urinate, but this provided little relief. So passed the night with the pain becoming more and more severe. I had originally hoped to wait until morning when I could attend my GP's surgery but by 3am I yielded to the intensity of the pain and phoned the locum doctor who immediately ordered an ambulance to take me to the Galway University Hospital. In retrospect, it seems that whilst in Iran where the temperature was in the upper 30's, I lost excess moisture through perspiration rather than urination but returning to the cool of Ireland, all unravelled.

Within a short time of my arrival at the hospital a catheter was inserted and the relief was immediate. Unfortunately this addendum has now become an *'inseparable companion'* but it was, of itself, insufficient to resolve the problem and an operation was necessary to relieve the pressure of the enlarged prostate on the urethra.

Some years previously I had drafted an *'advance directive'* with the assistance of my GP. I had given a copy to the urologist and asked that it be placed on my file; it included the provision:

In the light of my now having terminal cancer, I wish to further emphasize that in the event of the occurrence of pneumonia or of any other life threatening illness, I wish that no steps be taken to prolong my life and especially that no tube feeding should commence

Prior to surgery and having noted the advance directive, the anaesthetist asked as to what I desired should problems occur whilst I was under anaesthetic. This truly was *'crunch-time'*.

I responded that in the light of my terminal cancer diagnosis, I had on one side, a tsunami coming towards me which was likely to be painful and that if on the other side, a tsunami appeared which - though likely to kill me more quickly - would be less painful, than we should aim for the latter. Some time later and just prior to the commencement of surgery, the anaesthetist announced my wishes to the assembled team and asked if any of them had any objections, none did.

In the light of some cases which I had discussed in my PhD dissertation,³² I had been unsure as to whether my directive would be honoured. I was relieved and extremely grateful at the indications that it would.

³² One of the most disturbing cases concerned a 29-year-old English woman, Catherine, who in 1990 suffered a severe asthma attack whilst staying with her sister, Anna, in the United States. She had suffered from asthma most of her life and was well informed as to its management. Catherine agreed to go to a Massachusetts hospital but only if her treatment would be limited to the administration of oxygen. Anna called the hospital and was assured that Catherine would be treated only with oxygen. On attending the hospital, Catherine was given oxygen and medication through a nebuliser which she removed saying that the medication gave her a headache and that she wanted to leave the hospital. The attending physician concluded that intubation was necessary; meanwhile Anna telephoned their (physician) father who spoke with the attending physician and told him "... *that Catherine understood her illness well and that he should listen to her and not treat her without her consent.*"

An X-Ray showed that the cancer had spread from my prostate but the extent of the spread required an MRI scan which was listed for some weeks later, meanwhile the urologist - in discussing treatment options - urged hormone therapy as the only option available to me.

Recognising that my cancer was terminal, I emphasised that I had no desire for life-prolonging treatment and that my sole concern at this stage was to preserve my quality of life to the highest extent possible.

Remembering the debilitating effects of such treatment as recounted to me by a friend, I demurred. It was pointed out to me that his response was but the response of a single individual and that it would not be sensible to make a decision on such meagre evidence. I was surprised at the repeated urgings – almost an insistence (of both the urologist and her assistant) that I accept hormone therapy and at their assurances that it was not being proposed for any life-extending effects but solely because it would improve my quality of life. I resolved to reconsider my decision before my next meeting with the urologist by which time the results of the MRI scan would be available.

19th December 2018: Hormone therapy: the side effects

In an effort to determine whether my friend's extremely negative reaction to hormone therapy was unusual if not unique, I phoned the Irish Cancer helpline and spoke to an oncology nurse as to the possible drugs used in hormone therapy and their likely side effects. Though she was helpful, I realised that I needed more structured information and she recommended *The Health Products Regulatory Authority*.³³ This website was, essentially, a compendium of the package information leaflet for medicines and whilst some were

Catherine attempted to leave the hospital but was forcibly placed in a four-point restraint. She had been severely traumatized by her mistreatment at the hospital and swore repeatedly that she would never go to a hospital again.

Two years after the original incident she again had a severe asthma attack; she refused to go to hospital and subsequently died.

In subsequent legal proceedings, the Massachusetts Supreme Court reversed the decisions of lower courts which had upheld the restraint. At no stage had Catherine's competence been in doubt. (*over*)

... A report on the case in *the New England Journal of Medicine* in 1999, elicited a number of responses from medical practitioners who unanimously expressed the opinion that the disregard of Catherine's wishes and the subsequent use of coercion was appropriate.

³³ <https://www.hpra.ie/homepage/medicines/medicines-information/find-a-medicine>

extremely scant, others were informative but not presented in a form which suited my purposes.

Next I consulted the web-pages of the *US National Cancer Institute*,³⁴ the *Prostate Cancer Foundation of Australia*,³⁵ and the *Irish Cancer Society*³⁶ in the hope of finding information on the incidence and seriousness of the possible side effects from hormone treatment of prostate cancer.

Some side effects were rare but serious; leaving these to one side, of the less serious side effects, 'erectile dysfunction' was mentioned by all but in that I am now the proud(?) possessor of a catheter, that was a given.

In relation to 'hot flashes' the Irish Cancer Society notes that "over half of men who receive hormone therapy experience them."

The US National Cancer Institute suggested that

- *"For most ... prostate cancer patients, hot flash intensity is moderate to severe"* but that *"data regarding the pathophysiology and management of hot flashes in men with prostate cancer are scant"*
- *"Pilot studies of the efficacy of SSRIs [antidepressants] ... suggest that these drugs decrease the frequency and severity of hot flashes in men [but] there are concerns about the effects of hormone use on the outcomes of prostate cancer in addition to other well-described side effects."*

The Prostate Cancer Foundation of Australia reported that "... 34% to 80% of men on hormone therapy experience hot flashes" and that these may persist for up to five years of beginning treatment.

The Irish Cancer Society fact sheet also noted (but without giving percentage incidence) that hormone therapy:

- *"... can cause fatigue or extreme tiredness ..."*
- *"... bones can be less dense and become brittle and may be more prone to fractures ..."*
- *"... mood changes, poor concentration or memory problems, anxiety and sometimes depression ..."*
- *"... might also lose some of your muscle tone and strength ..."*

The US National Cancer Institute reported that hormone therapy:

³⁴ <https://www.cancer.gov/types/prostate/prostate-hormone-therapy-fact-sheet>

³⁵ <http://www.prostate.org.au/awareness/for-recently-diagnosed-men-and-their-families/advanced-prostate-cancer/treatment/>

³⁶ <https://www.cancer.ie/cancer-information/prostate-cancer/hormone-therapy-advanced-prostate-cancer#sthash.KdC71NWV.dpbs>

- "... can have substantial side effects ..."

- "... many of the side effects ... also become stronger the longer a man takes hormone therapy".

Furthermore:

- "Depression affects 15% to 25% of cancer patients ..."

- "Few studies Have addressed the issue of fatigue ... the only level 1 intervention for CRF at this time is exercise."

It concludes with the observation:

- "Many questions about the best uses of hormone therapy still need to be answered ..."

The Prostate Cancer Foundation of Australia noted:

- "Evidence shows that hormone therapy can affect how thought processes work. However it is not known for sure if this is a result of the hormone therapy or whether other side effects such as hot flashes and/or fatigue are part of the process."

Such a bleak list of side effects not only did not diminish my scepticism that hormone treatment might improve my quality of life, but considerably strengthened it. Although I had declined any life-prolonging treatment, a comment³⁷ from the *National Cancer Institute* made me wonder at the sanity of this whole treatment process.

20th December 2018: Decision-Time

Meeting with my urologist to discuss the results of the MRI scan, she informed me that the cancer had spread outside the prostate but not yet to the lymph nodes. She had also requisitioned the MRI scan from two years earlier but found it difficult to understand how I had been lead to believe that I then had only seven to eight months to live. Discussing this later with a friend, he suggested that medical consultants are – like the rest of us – to be divided into optimists and pessimists; clearly I had had one from each camp.

The urologist again recommended hormone therapy but was unresponsive when I detailed the list of side effects and when I wondered how my 'quality of life' could conceivably be improved under such a treatment regime. A chance conversation with a cancer nurse confirmed my belief that life prolongation was

³⁷ "Whether hormone therapy prolongs the survival of men who have been newly diagnosed with advanced disease but do not yet have symptoms is not clear."

the goal of the treatment.

I declined the hormone treatment.

Some weeks later, by chance, I read an article by an English academic who has long been an influential critic of the use of performance metrics as a guide to policy in relation to university reform; the essay had the intriguing title 'Kept Alive for Thirty Days'.³⁸ Though focussed mainly on the use of metrics in education, he gave an example from medicine:

"In New York State, for example, the report cards for surgeons report on post-operative mortality rates for coronary bypass surgery, that is, what percentage of the patients operated upon remain alive thirty days after the procedure. After the metrics were instituted, the mortality rates did indeed decline – which seems like a positive development. But only those patients operated on were included in the metric. The patients who the surgeons declined to operate on because they were more high-risk – and hence would bring down the surgeon's score – were not included in the metrics. In addition, patients whose operations had not been successful were 'kept alive for the requisite thirty days to improve their hospital's mortality data, a prolongation that is both costly and inhumane'.

University Hospital Galway is a 'centre of excellence' for the treatment of prostate cancer in Ireland and I wondered whether a similar system of 'performing to the metric' might be operative there; could it be that the ranking of the hospital might depend on the number of prostate cancer patients who survived a given length of time? My desire to forgo life-prolonging treatment, in favour of palliative care and an enhanced quality of life could simply not be accommodated within such a framework.

An unsettling thought!

21st December 2018: The winter solstice

When I first came to the Burren some thirty years ago it was to build a log cabin which I had hoped to have completed before the onset of bad weather. Like all such projects, complications soon arrived with the inevitable delays and winter soon arrived to be experienced from within the narrow confines of a small caravan. But what I had found most difficult to bear that winter was the absence of the sun.

³⁸ Collini, Stefan. 'Kept Alive for Thirty Days'. *The London Review of Books*. 8th November 2018.

Being on the north face of a mountain, the sun disappeared from my house for about six weeks centered on the winter solstice. By a strange coincidence this was about the same extent in time as in the north of Norway from where my ex-wife hails. I had spent some Christmases there and thought it a magical time: even the snow-covered graves had candles placed in memory.

Afterwards, heading south on the train, I noticed how my eyes were fixated on the southern horizon to catch the first glimpse of the sun; I had been told that in those lands, the first child to call out that they had seen the sun was rewarded with a free day for all the school. All this to show how visceral is our relationship to the sun.

In the following years back in the Burren, a strange reversal happened: it was now not so much sadness as the sun slowly disappeared into the caves of midwinter but the indescribable joy on its first reappearance and its slow journey back from its first alighting on the mast of a moored boat to its making landfall and then seeing my house bask in its full glory.

At this time last year I had stopped to wish an old neighbour woman well and commented that from now on the days would be getting longer. She demurred. The days would not be getting longer, she told me, until the cock crowed to the rising sun and that was about the 6th January. Puzzled and disbelieving, I kept track of the times of sunrise and sunset as given on my online weather site³⁹ where I was surprised to find that on the days following the solstice, whereas sunset was later with each succeeding day, sunrise remained static for about 10 days.

Remembering that in the Russian Orthodox tradition, Christmas is celebrated on 6th January which is also the date of *Nollaig na mban* in Ireland, a little reading uncovered that the term 'solstice' derives from the Latin sol ("sun") and sistere ("to stand still")⁴⁰, it seems that the Clare cock is considerably

³⁹ <https://www.yr.no/place/Ireland/Munster/Ballyvaghan/>

⁴⁰ Courtesy of Wikipedia: "*The word solstice is derived from the Latin sol ("sun") and sistere ("to stand still"), because at the solstices, the Sun's declination appears to "stand still"; that is, the seasonal movement of the Sun's daily path (as seen from Earth) stops at a northern or southern limit before reversing direction.*"

more perspicacious than his brethren in Wales, where as attested to by Dylan Thomas, the sun was well risen before the cock crowed.⁴¹

23rd December 2018: A reassessment

Just a few short months ago in Iran, I had energy: most days I would walk for hours exploring the cities like a *flâneur* - one who just strolls and saunters, just observing without any purpose or goal in mind just waiting to be surprised. This was my favourite way of 'appropriating' foreign cities - a few days, each day heading in a different direction, and one acquires an excellent intuitive grasp of a city. Now, to get the 100 meters or so to check my post-box, requires not only an effort of will but something akin to a plan or strategy.

The day that I finally left the hospital in Galway after my return from Iran, I booked a cheap flight to Agadir in Morocco for mid March - a 'carrot' to help draw me forward! I had been there before but used it simply as a base to further explore Morocco, this time my horizons have narrowed considerably and if each day I can get to the beach (even if by taxi) just to see the sun and sea, I will be more than thankful. The modest hotel into which I have booked serves an excellent breakfast (even including freshly squeezed orange juice) and luxury of luxuries, it has a lift so I need no longer run the gauntlet of fleets of steps lacking even the most basic of handrails.

Now I tire easily and sometimes sleep over 13 hours a night with an occasional additional nap during the day, leading me to wonder how bad I would be had I taken the hormone therapy with its high risk of additional fatigue.

In such circumstances and living alone, I began to fear that I would die in my bed and not be discovered for days creating quite a mess for those who had the task of packing me away. My eldest son (I have two sons Philip, the elder, and Peter) got me a Bluetooth sports watch which communicates my sleep pattern and my movements (or lack of them) to my smart-phone and thence to Philip's. I have thought of attaching this phone to the leg of a very energetic neighbour's dog - I would enjoy seeing the Philip's expression on seeing my 10k run before breakfast!

⁴¹ Dylan Thomas 'Under Milk Wood'. ... Captain Cat: "Too late, cock, too late"!

Though energy is low, I am lucky to have no pain although occasional discomfort. I have occasional headaches, lapses of memory and difficulty in spelling leading me to wonder occasionally if the cancer has spread to my brain but in that I have no intention to take any test to determine that question, I try to let such concerns slip away. This year I decided not to take the flu jab; at the back of my mind was the old saying that pneumonia is an old man's friend.

Most blessed of all is that I am in good spirits, able to read and still become infuriated at politics especially at Israel's treatment of the Palestinians and by the complicity and collusion of the West in remaining silent.

Now I believe that whilst the lines of Dylan Thomas "*Do not go gentle into that good night*", may well be apt when given to a younger man in the prime of life, they have no relevance for me. I believe that there is a time not to fight; a time to accept and simply to trust that in the words of Julian of Norwich, "*All shall be well, all shall be well, all shall be exceedingly well.*" A passage from a book⁴² on the swimmer as hero in fiction, deeply impressed me on first reading and has long stayed with me; it concerned the tactic adopted by divers who jumped from the top of the Niagara Falls into the whirlpool below and it was never to seek to fight the water or to seek to impose one's will as to do so ensured that one would drown; to trust, to simply trust!

Talk of '*fighting cancer*' or even '*conquering cancer*' sometimes seems to me, misplaced; what if, like Yeats, one were to pose the disturbing question "'*What then?*' sang Plato's ghost. '*What then?*'"

Beckett in a passage which I remember (but cannot trace⁴³) has his protagonist on waking each morning, check to see what pieces have fallen off during the night. A comment by the actor Billy Connolly is perhaps a little less bleak, but echoes the same thought and mirrors my own feelings exactly:

"As bits slip off and leave me, talents leave and attributes leave ... I'm near the end. I'm a damn sight nearer the end than I am the beginning.

⁴² Sprawson, Charles '*Haunts Of The Black Masseur: The Swimmer as Hero*'. Vintage Classics: 2013.

⁴³ Perhaps *Malone Dies*.

*But it doesn't frighten me, it's an adventure and it is quite interesting to see myself slipping away.*⁴⁴

25th December 2018: Christmas Day

Stocking my drinks cabinet was easy this year: prune juice from some of California's most prestigious 'prunereries'! The use of a catheter seems to exacerbate constipation and even the smallest tincture of alcohol gives rise to troubled sleep.

Both my sons invited me to join them and their families for Christmas Day but I opted to stay here alone; doing so, led me to reflect on my relationship with solitude. I enjoy my own company and I also enjoy the company of others especially when there is a deep friendship and easy familiarity; but I have a visceral need for solitude which I jealously guard; it is akin to a space where I can recharge my batteries; without it - to be perpetually surrounded by others - is for me, as in Sartre's famous aphorism, "*Hell is other people.*"

I believe that the need for solitude is akin to the need for silence; an old Arab saying has it that the proof of friendship amongst men is that they can be at ease in each other's company without a word being said. Conversely, I find the endless babble of conversation or the incessant noise of background music or television, exhausting. Even when I drive, it is generally in silence.

When and whence did this love of solitude and silence arise? As a young man I was gregarious but moving west to the coast with its unavoidable isolation led me to achieve what I once advised a friend moving west from the city "*The choice is stark: you must get to like yourself or else kill yourself.*"

I returned from a trip to Tibet over thirty years ago, with the beginnings of an interest in Buddhism. Later, spending some time in a Zen monastery in London, the teacher asked as to what had kindled my interest. My reply - that it had been in walking the mountains alone - sparked a snigger from other listeners, but a gesture of understanding from the roshi.

Solitude must be distinguished from loneliness, in my thirty years living in the Burren - sometimes with a partner, often alone - I cannot remember ever

⁴⁴ Sheperd, Jack. 'Billy Connolly says his life is 'slipping away'...' *The Independent*. 3 January 2019.

being lonely though that is not to say that sometimes I did not deeply desire that a special someone was by my side. Not only not lonely, but never bored - at the end of the day there is usually something that I had hope to accomplish but lacked the time.

Solitude and silence give space for a heightened creativity to emerge whether in academic work, more informal writing or working in wood. My most recent pieces – about which the *American Woodturner*⁴⁵ magazine commissioned an article from me - were suggested by how a shape can be carried across isolated objects and bestow on them a magical unity such as on a windswept hill, a tree is shaped by the rock behind which it shelters, the tree carrying onwards the shape of the rock. The physical piece was constructed by fixing some disparate shapes of timber to a base; immersing all in a container of water; placing in a freezer; turning the timber pieces encased in a block of ice on the lathe; watching the ice melt ... then *voilà!* Without the solitude and silence, I would never have had that inspiration.

Maybe I could not have come to Buddhism without my solitary mountain walks and the Zen meditation practice which has deeply shaped my character and understanding but looking back, I believe that the most profound character change was precipitated by reading an old Buddhist text written in the 8th century: '*The Zen Teaching of Huang Po*'.⁴⁶

First a word of clarification: Indian Buddhism is a highly intellectual exercise – subtleties and distinctions are its hallmark; Zen Buddhism, by contrast is anti-intellectual following in the traditions of Chinese Taoism. Zen can be austere, Taoism, however, delights in fun: two paths to the same destination.

I had first bought that text whilst attending a Zen summer school at Cirencester in 1993 and I see from the flyleaf, that I read it again in 1998 and 2001. I know also that I have read other copies because I suffer from the habit of underlining passages that I find insightful and so to read the book again with fresh eyes, I have had to buy new unmarked copies.

⁴⁵ Roche, Gerry. 'A Turning Theme Re-Inspired by Nature' *American Woodturner*. pp 32-34. February 2018.

⁴⁶ Blofeld, John (Trans.). *The Zen Teaching of Huang Po: On the Transmission of Mind*. Grove Press. (1994).

I still remember my experience on first reading it: utter shock and bewilderment. At university I had studied mathematics for many years and its intellectual methodologies had become second-nature to me – they were the bedrock of my personality; without them I imagined that I would be an empty shell. The intellectual arrogance, endlessly doubting, questioning and seeking to undermine, then the dismissal with disdain that which couldn't be 'proved' was as a reflex action, first against Catholicism but then everything became grist to the mill. Imagine then to read such as:

- *"So you students of the Way should immediately refrain from conceptual thought. Let a tacit understanding be all!"*
- *"If they would only eliminate all conceptual thought in a flash, that source-substance would manifest itself like the sun ascending through the void and illuminating the whole universe without hindrance or bounds."*
- *"The words of Gautama Buddha were intended merely as efficacious expedients for leading men out of the darkness of worse ignorance. It was as though one pretended yellow leaves were gold to stop the flow of a child's tears."*

Later reading Taoist texts, I found a similar perspective:

*"For Chuang-tzu the fundamental error is to suppose that life presents us with issues which must be formulated in words so that we can envisage alternatives and find reasons for preferring one to the other. People who really know what they are doing, ... do not precede each move by weighing the arguments for different alternatives. They spread attention over the whole situation, let its focus roam freely ... then the trained hand responds spontaneously with a confidence and precision impossible to anyone who is applying rules ..."*⁴⁷

It took many years of meditation practice before even a hint of such attitudes began to manifest. First, I noticed that when working on a piece of sculpture and when faced with a 'mental-block', my old habit was to push relentlessly on: to take a pencil or a piece of chalk and try to sketch or anticipate the possible next steps. Later, when faced with such a problem, I would put the unfinished piece in a position where it was not 'in mind' but was 'in sight' so that I passed it many times a day whilst working on other tasks; eventually *the* solution would present itself to me. I began to develop this as a strategy even in academic work: to examine a problem from as many angles as possible and from within as different contexts as I was able, *not* with the intent of coming to any immediate resolution but simply to drink in as much related

⁴⁷ Graham, A. C. *Chuang-Tzu The Inner Chapters*. Mandala (1986), p.6.

information as I could. Then begins the process of gestation, an unhurried leaving alone until a possible solution emerges.

Similarly in philosophy: relentlessly attacking a problem, nose to the ground, is akin to forcing a path through briars or barbed wire; shedding the aggression and standing back to give the problem space and air to breath, time will permit a solution can emerge – often from 'left field', utterly unexpected, original.⁴⁸ The important point is to trust; to have absolute faith that given time, all will resolve.

The process can be compared to exploring a strange city with a goal in mind⁴⁹ as against sauntering with eyes as wide open as is possible, uncritically, drinking in all.⁵⁰

To me, these differing stances can each be captured by an image:

- the cogitation, the deliberation, the cerebration and the endless rumination, by the image of a dog worrying sheep;
- the mind at peace, the body calm and in repose but utterly alert and missing nothing, by the image of a Buddha seated in meditation.

Dinner on Christmas Day was an Indian meal – lamb rogan josh with nan bread and yoghurt. After, some 'slow TV' – a two hour documentary on reindeer herders in Northern Norway. All in all, a wonderful day!

28th December 2018: Grandchildren

In the days after Christmas, both my sons visited each with their eldest child: Philip with Beth and Peter with Adam both grandchildren being just past the toddler stage. At that age, the immediacy in a child's responses; the intensity in their gaze; the strength of their grip, their absorption in what they are doing, evokes wonder. Not being a believer in any other-worldly heaven, I have interpreted the Biblical saying that one must become as a child to enter

⁴⁸ Some recent psychology books advocate a not dissimilar stance under the rubric of 'Right Brain' learning.

⁴⁹ Much like wearing goggles to blank out all that is not 'relevant'.

⁵⁰ "Bloom's 'journeying' in Ulysses bears many resemblances to Chuang-tzu's 'free and easy wandering.'" Mair, V.H. (Ed.) *Experimental Essays on Chuang-tzu*. University Of Hawaii. (1983); p.99.

heaven⁵¹ as an admonition that to live a contented life, one must shed some of those social masks often acquired to more easily navigate life in order to regain a little of that child-like simplicity of earlier days. Other spiritual traditions often advocate a similar perspective:

In Hinduism, the fourth stage of life is that of the *Sannyasa*:

*"Sannyasa is a form of asceticism, is marked by renunciation of material desires and prejudices, represented by a state of disinterest and detachment from material life, and has the purpose of spending one's life in peaceful, love-inspired, simple spiritual life."*⁵²

The *Tao Te Ching* urges that:

*"He knows all the time a power that he never calls upon in vain. This is returning to the state of infancy."*⁵³

*"Nearest then to Tao is the infant. Mencius in whose system Conscience, sensitiveness to right and wrong, replaces the notion of Tao, says that the 'morally great man' is one who has kept through later years his 'infant heart'."*⁵⁴

Erasmus in *The Praise of Folly* observes a little more harshly:

*Old people, furthermore, are not much different from infants: "both have whitish hair, toothless gums, a small bodily frame, and a liking for milk; both stutter and babble and engage in tomfoolery; both are forgetful and thoughtless; in short, they resemble each other in every respect. And the older they get the nearer they come to childhood, until like children, without being bored by life or afraid of death, they depart from this life."*⁵⁵

1st January 2019: New Year's Day

Before heading to Iran, I had placed my pot-plants out in the late summer sun hoping that they would survive in my absence. Returning after my hospitalisation, in the dying days of September, all were well except one old Christmas cactus whose remaining flowerless fronds broke off in my hands. Pushing both back into the compost, I had little hope that they would survive but to my amazement both flowered profusely over the coming months until in

⁵¹ Matthew 18:3 "And said, Verily I say unto you, Except ye be converted, and become as little children, ye shall not enter into the kingdom of heaven."

⁵² <https://en.wikipedia.org/wiki/Sannyasa>.

⁵³ Waley, Arthur. *The Way and its Power*. Unwin (1987); *Tao Te Ching*, Chapter XXVIII.

⁵⁴ *Ibid.* p.55.

⁵⁵ Mair, V.H. *Chuang-tzu and Erasmus: Kindred Wits* in Mair, V.H. (Ed.) *Experimental Essays on Chuang-tzu*. University Of Hawaii. (1983). p.93.

the dying days of December the plant shrivelled and died⁵⁶ – as if it had hung on just long enough to give of its best. When on New Year’s Day, I went to put it outside, I noticed a flicker of light on the rocks furthest from my house: the sun was on its way back.

Truly one door doesn’t close but another opens!

In recent years, when suddenly startled by a rainbow or glimpse of sunlight or a heron or robin, I have often caught myself making an involuntary bow – a gestures of gratitude; to what? I have not the remotest idea!

Soon, if my diminishing strength permits and all else goes according to plan, I head to Morocco and it is now nearly time to start packing and – most importantly – topping up my hipflask with prune-juice!

"... to be continued"

June 2019

The note of optimism in writing *'to be continued'* was somewhat tongue-in-cheek – a *'whistling past the graveyard'*; I did not imagine that six months later I would still be alive. This belief stems in part from a comment made by my original urologist some three years ago (when I expressed a desire to travel to Russia to see the Caucasus the following spring) that it would not be possible which I had interpreted as implying that I had but months or maybe at most a year to live. This urologist had been attached to a private hospital and on being hospitalised on my return from Iran, I was now in a public hospital and under a different urologist who was much more optimistic and who, some months ago, suggested that though the cancer had spread outside the prostate, *"I had years to go"*.⁵⁷

⁵⁶ I was being unduly pessimistic because, over the following months, a glimmer of life reappeared. Many months later, a frond 2" high, proudly proclaims its tenacity and vitality. Nature again teaching me a lesson.

⁵⁷ As I write this, an article appeared in the *New York Times* by BJ Miller (a hospice doctor) entitled: *"Don't Tell Me When I'm Going to Die. Prognoses are more of an art than a science. Maybe it's better not to know."* He writes:

"... When faced with serious illness, being able to make decisions about the flow of information is one of the most life-affirming things you can do. It's a way to declare: I

I fully understand that in matters such as these, precision is something of a chimera and that to pursue the question of which prognosis is correct, would ultimately be a fruitless exercise – a distraction from the important question of how best to live well in the time that remains howsoever long that may be. What I find interesting now is the question of how the pessimism or optimism of a prognosis affects the attitude to life of the one receiving the diagnosis – had my first consultation been with the second urologist (the optimist) rather than the first would that have affected how I lived my life over these last three years?

In essence, this is a question of whether it is better to keep in mind the brute fact of one's mortality or to relegate it to the back of one's mind.⁵⁸

I well remember when the importance of this question first came to my attention and it was many years before my encounter with either philosophy or prostate cancer. It was in seeing a film *'The Sheltering Sky'*⁵⁹ which was based on a book of the same name written by Paul Bowles. Of all films which I have seen which seek to portray a man's encounter with the desert, that film is to me, supreme in that it captures both the mystery and majesty of the desert and also man's existential aloneness which is hinted at even in the title:

'You know', said Port ... 'the sky here's very strange. I often have the sensation when I look at it that it's a solid thing up there, protecting us

am alive, and it's still my right to choose what's best for me.... But the choice not to know can also be liberating. You can say, "No thanks, I opt out." "

And notes: "Studies have long shown that physicians are particularly prone to overestimating life expectancy – especially when they like their patient."

<https://www.nytimes.com/2019/06/22/opinion/sunday/death-disease-life-expectancy.html>

⁵⁸ In an article entitled "How Long Have I Got Left?" by Paul Kalanithi (a 36-yr-old doctor) he described his response on seeing his own scan: "Widely metastatic disease – no role for surgery". Treatment was successful; but the experience had taught him some lessons:

... "I began to realize that coming face to face with my own mortality, in a sense, had changed both nothing and everything. Before my cancer was diagnosed, I knew that someday I would die, but I didn't know when. After the diagnosis, I knew that someday I would die, but I didn't know when. But now I knew it acutely. The problem wasn't really a scientific one. The fact of death is unsettling. Yet there is no other way to live. ... I remember the moment when my overwhelming uneasiness yielded. Seven words from Samuel Beckett, a writer I've not even read that well, learned long ago as an undergraduate, began to repeat in my head, and the seemingly impassable sea of uncertainty parted: "I can't go on. I'll go on." "

<https://www.nytimes.com/2014/01/25/opinion/sunday/how-long-have-i-got-left.html?action=click&module=RelatedLinks&pgtype=Article>

⁵⁹ *'The Sheltering Sky'* (1990). Bernardo Bertolucci director.

from what's behind.' ... Kit shuddered slightly as she said *'But what is behind?'*... *'Nothing, I suppose. Just darkness. Absolute night'*⁶⁰

A scene early in the film shows the three young people (Port, his wife Kit and a friend Tunner) recently arrived in Algeria and now sitting in a café planning their trip. The author Paul Bowles making a cameo appearance, sits close by, watching and listening; he muses:

'Death is always on the way,' Port had said, *'but the fact that you don't know when it will arrive seems to take away from the finiteness of life. It's that terrible precision that we hate so much. But because we don't know, we get to think of life as an inexhaustible well. Yet everything happens only a certain number of times, and a very small number, really. How many more times will you remember a certain afternoon of your childhood, some afternoon that's so deeply a part of your being that you can't even conceive of your life without it? Perhaps four or five times more. Perhaps not even that. How many more times will you watch the full moon rise? Perhaps twenty. And yet it all seems so limitless.'*⁶¹

That question *'How many more times will you watch the full moon rise?'* seared into my consciousness to the extent that ever afterwards it was the uninvited guest whenever I saw a full moon. Now with my cancer on the march I pose a similar question when I hear the first cuckoo, or glimpse the blossoms open on the whitethorn or the first flowers on the fuchsia – *Is this the last time?*

To answer the question posed earlier I believe that having in mind the awareness of one's own death much of the trivia of life falls away and that when the first call of the cuckoo is heard, it is heard with an intensity which would otherwise be absent.

When travelling and encountering some stunning vista, I seldom reach for my camera rather I seek to 'drink all in' knowing that this was my one and only chance to see that which was in front of me. Other travellers – especially Japanese – often travelled with a multiplicity of cameras; watching them is disheartening - like seeing a child choose the gaudy ersatz over the true; or in an old Buddhist metaphor, seeking to capture the wind in a net.

⁶⁰ Bowles, Paul. *'The Sheltering Sky'*. London: Penguin Modern Classics. 2004. p. 99; and at p.366:

"Someone once had said to her that the sky hides the night behind it, shelters the person beneath from the horror that lies above. ... At any moment the rip can occur, the edges fly back, and the giant maw will be revealed."

⁶¹ *Ibid.* p.253.

Gandhi who once said *'Live as if you were to die tomorrow,'* urged a similar intensity but in his wisdom, added *'Learn as if you were to live forever.'* This ensures that the awareness of one's inevitable death does not lead to an intellectual paralysis much like that of a rabbit caught in the headlights of an oncoming car.

Tolstoy in his novella *"The Death of Ivan Ilyich"*⁶² explores how an approaching death rents the veils of ignorance and denial which had enabled the protagonist to do his duty *"... duty – that is to lead a decorous life that is approved of by society"*⁶³. He had only an intellectual acceptance of death:

Ivan Ilyich knew in the very depths of his soul that he was dying but not only could he not get accustomed to this, he simply didn't understand it; he just couldn't understand it. All his life the example of a syllogism ... - "Caius is a man. Men are mortal, Therefore Caius is mortal" – had seemed to him to be true only in relation to Caius but in no way to himself."

His friends and family colluded with him in this denial as did his doctors in their pretence that his dying was not inevitable but that some different treatments could rescue him.

He wondered why such an illness had been visited upon him:

*"But if I could just understand why. That too I can't. I might be able to explain it if I said I had lived not as I should have. But it's impossible to admit that" he said to himself remembering all the lawfulness, the correctness, and the decorum of his life.*⁶⁴

In the days that followed he watched how those around him behaved:

*"He saw in them himself, everything by which he had lived, and saw clearly that all this was wrong, all this was a terrible, huge fraud concealing both life and death."*⁶⁵

The lesson that I have taken from Tolstoy is that fulfilling social expectations - 'duty' - and worldly success are not the guides with which to fashion one's life rather the obligation is to look deeply into one's heart and live so that on one's deathbed, looking back, one should be as proud as one can be of the choices that have been made irrespective of whether they led to success or to failure.

⁶² Tolstoy *"The Death of Ivan Ilyich & Confession"*. Peter Carson (trans.) Norton; New York, 2014.

⁶³ *Ibid* p.48.

⁶⁴ *Ibid* p.103

⁶⁵ *Ibid* p.105

Tolstoy wrote his novella when he was in his fifties and had yet another twenty-five years to live. Then, aware of death approaching, he left wife and family with these words of explanation:

*"I am doing what old men of my age usually do: leaving worldly life to spend the last days of my life in solitude and quiet."*⁶⁶

- an attitude which I note that I have increasingly embraced and which on reflection, is quite different from that of six months ago when I went on holiday to Agadir.

Agadir

I had travelled to Agadir many times before and my most recent being in 2018. Now my flight had been booked for 21st January but from early that day a snowstorm began to envelop Dublin and it seemed that my flight would never get off the ground; nevertheless – though my flight was not to depart till 9pm - I headed to the airport at 10am. As more and more flights were cancelled, the airport became increasingly crowded and chaotic but because my plane was travelling up the west coast of Africa to Dublin, it not only arrived but managed to depart from a Dublin airport that then reminded me increasingly of the chaotic US evacuation of Saigon!

Agadir itself is not of great interest, the old city having been destroyed in a severe earthquake in 1960 which killed about 15,000; it was rebuilt in the manner of a European town with wide streets and open spaces but it still has the inestimable advantages of sea and sun. In 2018, I had headed to Taroudant in the Atlas mountains and over Tizi n'Tichka mountain pass to Marrakesh. The mountains and the road over the pass, were spectacular but I was lucky to get that far: sitting at the communal table for breakfast in the small hotel in Taroudant, a fellow guest – a Belgian - breezed in introducing himself arrogantly as a '*NATO Officer*'; perhaps he was expecting praise but his manner so got under my skin that I asked was it not something to be ashamed of in view of the havoc NATO had wrought in Afghanistan and Libya. Had that comment of mine been made not at breakfast, but in the evening over a few whiskeys, I doubt that it would have ended so peaceably.

⁶⁶ *Ibid* p. 9

2019 was a different experience than 2018; this time not only had I no energy for mountains but steps – especially those without handrails – had become a serious obstacle. Nonetheless I managed to find a reasonably level route between hotel and the cornice which I slowly navigated each day – I realised that I now had to learn to appropriate the city differently – now banks of steps to be avoided and toilets to be close at hand are the necessities to be always kept in mind. I had one ‘mishap’ where the catheter valve loosened itself and suddenly urine ran down my leg; my trousers were light coloured and the staining was evident and thus attired I had to make my way across the town back to my hotel room. I realised that this was a new phase and was a ‘shedding of dignity’ which I would have to get used to and accept. Later using a combination of fishing line, elastic bands and insulating tape “*I finally reached a solution, inelegant assuredly, but sound, sound.*”⁶⁷

My energy was low: often after breakfast, having checked the online news, I would have a 45 min. nap; I would retire to bed for the night by 8pm; my days were becoming increasingly constricted. It was a surprise to see how over a few short months, things had begun to unravel. Nonetheless I was in good spirits.

The goal of my daily strolls was the sea which, over the years has become something of a drug to me – miss it for a few days and I begin to get withdrawal symptoms. At the cornice, I would watch tourists, Moroccans, the other African street vendors and their interactions. The European tourist couples strolled hand-in-hand but I often got the impression that – rather than it being a gesture of mutual affection – it was an expression of support or indeed defiance, against the African ‘other’. As a European, I found it intriguing to see the ease of the interaction between the African street vendors, their sharing of food, their sense of fun and joy of life despite their evident straightened circumstances – a deep contrast to the reserved, leather-skinned Germans not quite marching in step.

⁶⁷ Samuel Beckett. *Molloy: ‘the stone sucking scene’.*

In 1972 I was awarded an MPhil in Pure Mathematics by TCD and - in that the main body of which was a proof of c. 160 pages (in a discipline where conciseness is the hallmark of elegance) – I had intended to use this Beckett quotation on the title page but ‘chickened out’. Now I have finally got my chance!

One event especially stands out in my mind: a Moroccan, in his mid-thirties who walked with a slight limp was selling sun-glasses; he approached me but whether because of my unfashionable clothes - an 30yr-old Lowe desert jacket with no less than eight pockets (each of which had a designated purpose so that if stopped, I knew which contained my passport, which my small notes, which the larger) – my age or my friendly refusal, he realised I was poor customer material. He sat down close by and we began a sparse, languorous conversation peppered by long, but comfortable, silences. He told me that as a child, he had suffered from polio and that times were difficult especially because one recent morning his wife getting out of bed, suddenly told him she was leaving him ‘just like that’. After a long silence he said “*we are all born alone*” to which I could only respond “*we all die alone*”. In the retelling, it seems such an innocuous event but to me the shared silences and the few words bespoke a tentative comradeship – voyagers on a journey “*So we beat on, boats against the current, borne back ceaselessly into the past.*”⁶⁸

Twenty-five years earlier a similar experience had happened to me at the Giza pyramids in Cairo. Seeking to avoid the tourist crowds, I sat at one of the smaller pyramids, at peace, as I looked over Cairo and the Nile. A hawker approached offering a ride on his camel. Having realised quickly that he was on a ‘hiding to nothing’ he sat down close by but as his English was limited and my Arabic was non-existent, we exchanged but a few scattered phrases. He asked my nationality and my destination. It was December and I was heading to the north of Norway *via* Moscow. Attempting to give him some inkling of Norway in winter, I told him that there the sun vanished completely and that it was snowing and dark and that at Christmas people placed lighted candles on the snow-covered graves of their forbearers. Feeling the warmth of the sun, he looked at me with a deep compassion.

Some days later whilst browsing in a university bookshop in Cairo, I came across and bought a book entitled ‘*Rationality*’⁶⁹ a subject which having completed postgraduate studies in both mathematics and logic, I had a deep interest. However the book lay unopened until many years later I brought it

⁶⁸ F. Scott Fitzgerald. ‘*The Great Gatsby*’. last lines.

⁶⁹ Manktelow & Over (eds.) ‘*Rationality; Psychological And Philosophical Perspectives*’. London: Routledge; 1993.

with me as headed for a short holiday in Agadir and it was on the beach above which I now sat that I first began to read it not realising that it was to preoccupy me for the following twelve years until I finally completed my PhD in 2011.

Choosing some books to bring with me to Agadir I found on my bookshelves not one but two copies⁷⁰ of the Russian poet Joseph Brodsky's '*This Wild Darkness: The Story of My Death*'⁷¹ which describes his voyage towards his death from AIDS. It is an extremely courageous and unflinching look at the ebbing of his life. In his struggles and discomfort he had his wife by his side; I would be alone but for that I had no one to blame but myself. Peter Noll was also alone but spoke about how his cancer diagnosis had precipitated the ending of one long-standing relationship which "... *has hurt and troubled me deeply.*"⁷² For some, another's impending death seems to presage a speedy exit stage left; thankfully there are others who take it as a sign to redouble their kindnesses, generosity and friendship. Bless them.

Just before heading to Agadir, I thought of how dispiriting it would be to return home without any more journeys to look forward to - to what would likely be my 'final resting place'. I booked a flight to Tbilisi for early April - 'April Fool's Day' seemed especially apt. I had spent a month in Tbilisi in 2013 but then I had travelled south to Armenia, this time I hoped to travel north to get another glimpse of the Caucasus. One image of exile and longing from my travels in Armenia still haunts me: it was of Mount Ararat as seen from Armenia's capital Yerevan. To Armenians, Mount Ararat is a sacred mountain yet it is in Eastern Turkey but because of deep political divisions between Armenia and Turkey, Armenians are unable to visit the mountain, yet Ararat is clearly visible from Yerevan - rather Ararat seems to be the very focus of Yerevan's streetscapes; and because of mist and smog, the lower reaches of the mountain are not

⁷⁰ Both unread. Over the years I had set aside books which I thought I would need at some stage of my life; indeed my Kindle is full of such books as is my Walkman full of music to guard against the day when I may be confined to a hospice bed. I thought it might be useful in light of this journal which I am now writing.

⁷¹ Harold Brodkey. *This Wild Darkness: The Story of My Death*. London: Fourth Estate.(1998)

⁷² Noll, p.14.

visible, but the snow capped mountain has an ethereal presence – spiritual, heavenly, its tethering to the earth cast away.

Whilst in Agadir I had noticed a small swelling on my cheek and visiting my doctor on my return to Clare, he suggested a biopsy. It was positive for cancer. We also discussed the possibility of hospice care in the event that I would no longer be able to manage to live on my own; my local hospice is in Ennis but my preference was for Galway as it would be closer to friends and to my sons, and he took the initial steps to put the process in place. Over the following months I had visits from both a hospice nurse and a health board nurse in addition to the nurse who replaced my catheter at 3-monthly intervals; all extremely helpful and friendly.

On mentioning to a friend that a hospice nurse had just called, she suggested that, rather than a hospice *'which would be awful'*, I should go for a long swim. Thus ended that friendship!

Over the 30 years that I have lived beside the sea, I have seen rescue teams walking the shore in search of the body of a suicide; often these are young Galway students who, perhaps drunk, overcome with depression or a break-up in a relationship, throw themselves off a bridge into the Corrib river. The burden on the family and friends of such a death can barely be imagined especially in the guilt occasioned by such a death and the endless self-questioning it would precipitate: *'what might I have done?'*

Suicide in the case of the extreme pain often suffered in the final stages of terminal cancer raises different questions – the suicidal gesture perhaps open to being interpreted as a the sundering of relationships. Assisted suicide obviates such fracturing and permits the saying of final good-byes but such is not legal in Ireland. In 2013 Marie Fleming who had been diagnosed with Multiple Sclerosis and was in the terminal stages of the illness when she and her partner began legal proceedings against the State. Fleming no longer had the use of her limbs and said she wished to die at the time of her choosing and with the assistance of her partner as she was not physically capable of taking direct action herself. However she did not want to risk the potential legal repercussions for her partner, who could have faced 14 years in prison for

assisting her. The Supreme Court held that the right to life in the Constitution does not import a right to die and said there was no express right in the constitution to commit suicide or to arrange for the termination of one's life at the time of their own choosing. The Chief Justice added that there was nothing in the judgment to prevent the State from introducing legislative measures, with appropriate safeguards, to deal with cases such as Ms. Flemings.⁷³

Whilst it is understandable that for the court to take a contrary decision might have trespassed on the powers of the legislature, to simply pass the problem in its entirety back to the legislature was - in view of the extremely conservative nature of Irish politics - a less than courageous decision. The strategy adopted by the Canadian Supreme Court in similar circumstances was to be admired: in 2015 the court held that for it to simply declare the right of adults with grievous and irremediable medical conditions to be entitled to physician-assisted suicide, would cause considerable legal uncertainty and in the absence of detailed safeguards, might put the lives of others in danger hence the court decreed that it would delay the coming into force of a right to assisted suicide (which it termed '*medical assistance in dying*') for twelve months to permit the legislature to enact its own detailed legislation. There have been tentative moves in Ireland to put assisted suicide on the political agenda such as a bill tabled by Minister John Halligan, but judging by my experience in the 1983 anti-abortion referendum⁷⁴ (where the debate often became extremely heated if not, vicious) and in attending an *EXIT* conference⁷⁵ in 2013 on assisted suicide, the campaign for assisted suicide in Ireland will be much more contentious than was the campaign on abortion.

⁷³ Dearbhail McDonald 'Marie Fleming loses Supreme Court right-to-die case' *Irish Independent* April 29 2013 [<https://www.independent.ie/irish-news/courts/marie-fleming-loses-supreme-court-righttodie-case-29228686.htm>]

⁷⁴ My then pregnant wife Mette and I took a constitutional case against the State arguing that the proposed wording, in speaking of the *equal* rights of the mother and foetus and without clarifying what should happen in case of conflict, was in its ambiguity, irrational. We lost our case in the High Court.

⁷⁵ *Exit International* seeks to promote the right of terminally ill people to assisted suicide. Because of a bomb threat, gardai were present at the conference. Being one of the first to leave the conference, I was filmed in an extremely aggressive manner by someone I understood to be a member of *Youth Defence* - an organisation which had lead an extremely militant campaign against the legalising of abortion.

As to my own case, I have been assured by my doctors that if extreme pain develops, excellent palliative care facilities exist in my Health Care area, but that is no doubt, a matter which I will, in time, discover.

At present I have some discomfort but little pain or depression; sometimes my breathing is very laboured and my energy is low; I often sleep 12 hours a night with a further 1-hour afternoon 'nap'.

I notice now how my memory occasionally fails – even for the spelling of some common words; my solution is to put what I know to be a misspelling, into a Google search box and hope that it will come up with some suggestions, but I see no point in seeking medical 'remedies' for this. To be diagnosed as having pre-dementia cognitive impairment or Alzheimer's would be a masochistic endeavour – akin to putting an additional burden on my back and to no point in that no corrective is available. I'm tempted to say that with luck, my body will fail before my mind but, on reflection, this might not be wise; perhaps the best course is simply to trust that all these question will resolve in the end.

Surgery to remove the cancerous protrusion on my cheek had been scheduled for mid-March. The plastic surgeon who was in his mid-thirties, having given me a local anaesthetic, explained the procedure which involved making a 3" diameter circular incision. How it happened I do not remember but we began exchanging travel memories: he particularly enjoyed travelling in South America where I have never been whereas my preference was for Asia - especially Islamic states - and Russia and the countries of the old Soviet Union. He mentioned that he seldom used a camera and his preference was to travel alone – that way one had to keep one's eyes peeled and consequently saw much more; furthermore locals were more willing to interact with a sole traveller; his colleagues could not understand the virtues of such travel but it was a mirror of my own views. Imagine my surprise when he told me that his most recent trip had been to Kazbegi in Georgia in the midst of the Caucasus – the very place I was going in barely two weeks time!

Not only was he a good traveller but also an excellent surgeon as the extensive scar on my face healed rapidly and well.

On leaving the hospital, I strolled slowly around Galway but so slowly and laboured that at times it seemed like I was rowing a currach on dry land; despite that, it was a beautiful warm sunny day which gifted me a sense of exuberance and the freedom of an old eccentric: coming across a parked empty hearse with its rear door open and two undertakers standing in attendance, I quipped "*Are you touting for business?*"

Seeing my slow progress around Galway, I began to fear that as my flight to Tbilisi was *via* Istanbul, whether I would be capable of navigating the distance between the landing and boarding gates, Istanbul's new airport being especially large. I need not have worried: Turkish Airlines provided a wheelchair and an attractive young woman to accompany me! This was not my first voyage in a wheelchair: some two years earlier my arrival and departure times allowed for less than an hour and because the plane was delayed in leaving Dublin, I feared that I might miss my flight when I chanced to an empty motorised wheelchair. The attendant did not speak English and I had no Turkish but waving my boarding card, he understood my difficulty. Travelling at speed and with my walking stick held straight in front like a lance, fellow travellers scattered and I felt something of the exhilaration of a Don Quixote.

Revisiting Tbilisi after 6 years was something of a shock - the city has been transformed both architecturally and atmospherically. Now it is a haven for the youth of so many nations and not only is it friendly and bubbling with creative energy but it is amazingly cheap: a good coffee and some chocolate cake cost just over €2!

I spent a week in Tbilisi before I headed north for Kazbegi. Tbilisi had been basking in late spring sunshine which, on heading north, soon turned to snow and the last 10k before Kazbegi was a whiteout - I was back in winter and that night I might as well have been on the moon as visibility was close to zero. The following morning all was transformed - clear blue sky and the town was surrounded by snow capped mountains with Mt. Kazbek lording over all and on a shoulder of the mountain high over the town, was the Tsminda Sameba monastery and it was it that caught the first glimpse of the morning sun.

Both the mountain and the monastery were framed by the window of my rooming-house and, during the night on my many visits to the toilet (one consequence of the catheter) I would often see both under the light of a crescent moon – my feelings for such mountains is akin to worship!

One tale about mountains that has an especial resonance with me is that of Edmund Hillary and his sherpa, Tenzing Norgay, on the first ascent of Everest: Norgay refrained from taking the final step to the summit as it would be a disrespect to a mountain which was sacred to him. The very idea of 'conquering' Everest would be to him, a blasphemy.

I stayed in Kazbegi for ten days and each morning made my way slowly to the restaurant on the main square for my breakfast of two fried eggs and coffee. (In travelling, I keep a photo of two fried eggs on my smart phone in case of language difficulties!) Breakfast was followed by a short stroll, finding a vantage point and then watching the comings and goings of which there was no shortage as Kazbegi is the last town on the road to Russia.

After breakfast on my last morning, I went to pay and was told that as an 'honoured guest', this morning's breakfast was free. I was suddenly overcome with emotion and much to my embarrassment, tears came to my eyes. Feeling a sense of shame for my display of emotion, I made a speedy exit mumbling a heartfelt thanks.

Just before travelling to Tbilisi, I had booked a flight to Agadir so that on my homecoming I would have something to look forward to. Arriving back in Clare and remembering how bereft of energy and strength I was when in Tbilisi, I reckoned the next trip would draw the final curtain on my travels. Realising that, I decided to cancel the trip to Agadir and aim for something a little more adventurous: perhaps a flight to Uzbekistan to visit the much fabled cities of Samarkand and Bukhara. Some years earlier whilst in Kyrgyzstan I had attempted to travel to Samarkand but border clashes and visa difficulties made it impossible.

Back from Tbilisi, I with four friends from college days headed to a small hotel in Rosses Point for a few days to share reminiscences over a few pints. It is something that we have done over the last five summers and in that two of

these friends must travel from abroad, I am deeply grateful. A few pints with old friends, a good meal, excellent conversation and topped off with, perhaps, a glass of Courvoisier is an excellent tonic and I can feel life flowing back into me.

16th August 2019

My flight, *via* Istanbul, is booked for 3rd of September; I land at Samarkand, stay five days and then head to Bukhara for five days and then back to Samarkand before heading home – that, at least, is the plan!

I booked my hotels in Samarkand and Bukhara and requested a quiet room with easy accessibility and, if possible, with a good view. The Bukhara hotel responded promptly but much to my amazement I received the following reply:

Dia duit daor Cerry Roche ! Táimid an-sásta go rinne Tú an rogha de ár n-óstán. Ar Do cheist : a Chuirimid ar fáil duit le seomra ar an dara hurlár sa bhloc N°1 le íseal staighre agus beidh sé Cabhrú leat chun dul suas agus síos, a ardú agus níos ísle Tá muid ag fanacht le bualadh leat agus a chruthú Uasta áiseanna do Do fanacht agus a chuid eile i ár n-óstán. Maidir le riarachán.

I replied in English but the response was again in Irish and I realised that my replying thus was discourteous so – my school Irish being poor – I had to have recourse to Google Translate! Google talking to itself but it was a beautiful gesture and I'm looking forward to meeting the writer.

Over the last few weeks a young Swedish schoolgirl, Greta Thunberg, has been much in the news over what began as a one person protest against the unwillingness of politicians to take meaningful steps to combat climate change. Her campaign grabbed the public imagination and she has been the subject of much media coverage some of it quite aggressive even vitriolic.⁷⁶ I admire her bravery and her ability to set forth her arguments (with which I am in complete sympathy) but it is not her activism that has captivated me in recent

⁷⁶ 'Greta Thunberg hits back at Andrew Bolt for 'deeply disturbing' column.' *The Guardian*. 2nd August 2019:

...The highly personal character assassination published in Rupert Murdoch's tabloids repeatedly referred to Greta's mental health, saying she was "deeply disturbed", "freakishly influential" and "strange"... "I have never seen a girl so young and with so many mental disorders treated by so many adults as a guru," Bolt wrote....

<https://www.theguardian.com/environment/2019/aug/02/greta-thunberg-hits-back-at-andrew-bolt-for-deeply-disturbing-column>

weeks but the fact that she describes herself as having been diagnosed with Asperger syndrome which is a form of high-functioning autism. Interestingly, she sees her condition not as a disability, but as a '*gift*' which has helped open her eyes to the climate crisis.⁷⁷ This syndrome and the recent discussion around it, have made me re-examine something of my own history from close to fifty years ago.

Mathematics was my strongest subject in school and not knowing that it was possible to take a degree in Pure Mathematics, I enrolled in Engineering. I did well in my first year exams and having discovered the possibility of specialising in mathematics and found an obscure regulation that permitted one who had a high marks in first engineering mathematics to transfer to second year Pure Mathematics, I decided to take that path. I approached the Professor of mathematics who advised me not to attempt to transfer to second year, but to begin again in first year mathematics. Arrogantly, I decided to take a year out and to read on my own the first year courses and then transfer to second year as that would exempt me from the first year examinations. The following academic year I attended the second year mathematics at the beginning of term but quickly realised that I was entirely out of my depth – not in the sense of going from the shallow end of the pool to the deep end but rather a headless dive into the turbulent ocean waters of the 'Roaring Forties'. Having rejected the advice of the professor and now seemingly shipwrecked on the rocks, I sought a solution, *any* solution.

I approached the student advisory service and made an appointment with a councillor who turned out to be a psychiatrist, Dr. Fahy, and who was deeply sympathetic to my plight and suggested that I now take the advice originally given to begin at first year and that he would write to the Department pleading my case; he also prescribed the then 'wonder-drug' valium/librium to ease my anxiety. The Department accepted his recommendation and I began again at the beginning but with the 'baggage' of now being somewhat dependant on these anti-anxiety drugs. I graduated with honours and was offered a position as lecturer in mathematics at the recently established Regional College in Sligo.

⁷⁷ *Ibid.*

Three years down the line and dissatisfied with my teaching job, I decided to return to College and begin a philosophy degree. Having been accepted to TCD but having little money I decided to continue teaching for the two months until college registration and having vacated my flat, took a small room in a rooming house; a relationship broke down and I was drinking heavily, still on the anti-anxiety medication and decided to postpone the college registration for a year. Heading towards Christmas and feeling things going adrift, I decided to make an appointment with the psychiatrist from my college days. Turning up for the appointment it was not he but his locum – a Dr. Tubridy - that was in attendance and who suggested that once Christmas was over, I spend a couple of weeks in John of God mental hospital to enable me to get my life back in order. The prospect of a break was attractive and, not realising the consequences of spending time in a mental hospital, even if voluntary, I accepted his suggestion – a most unwise decision on my part.

I spent about a month at the hospital but some days before leaving the hospital, what transpired to be a very unpleasant surprise was in store for me: I was requested to attend an interview which took place around a large table and the questioning and discussion was informal and relaxed. Dr. Tubridy was present as was a second psychiatrist whom I had not met before and a nurse from the ward, and perhaps five others who may well have been psychiatric interns or students or social workers. As far as I can remember, no difficulties or problems arose at the interview and when it was over I was asked to wait outside for the second psychiatrist to have a few words with me.

This second psychiatrist was a Dr. Shanley. I had been in the same class at Belvedere College as his younger brother Peter, and he himself had been in a class two years ahead of us. I had a vague recollection of seeing him in school but had not seen him since and did not know that he was a psychiatrist.

Dr. Shanley gave no sign that he recognised me or indeed that we had anything in common. The meeting lasted but a matter of minutes and his manner was abrupt. He told me *"You have schizophrenia, it is a serious illness and you will be on powerful medications for the rest of your life"*. With that the interview ended!

I was dumbfounded, shocked, stunned. The term 'schizophrenia' had never been used in relation to me by Dr. Tubridy nor by Dr. Fahy, – both of whom had spoken of my depression and anxiety – nor by anyone else and it filled me with fear and foreboding. Also my medication had been changed – no longer anti-anxiety but anti-psychotic drugs.

Living in a pre-internet age, information about schizophrenia was hard to find; I gleaned whatever little I could in various bookshops and libraries. The consensus as far as I could determine it, appeared to be that a schizophrenic was one who 'heard voices' and had lost touch with reality: examples given were the those who believed that they were Jesus Christ or who believed that the TV was speaking to them and urging them to commit heinous acts.

Though I was a shy bookish person who enjoyed my own company – and on those grounds could be described as a bit of a loner who was sometimes oversensitive and – when entering a room full of people, sometimes imagined them talking about or being critical of me, I had never 'heard voices', never had hallucinations or delusions. On those occasions when I imagined people being critical of me, I fully accepted that this may have been an over-interpretation or mistake on my part so the diagnosis of schizophrenia that had suddenly been visited upon me, left me shattered. The degree of confidence and self-assuredness that I had been able to regain during my stay in the hospital, was – in those few words – stolen from me.

I left the hospital carrying a greater burden than when I entered but with a determination not to be overwhelmed.

Taking anti-psychotic medication meant that I continued to attend psychiatrists none of whom accepted Dr. Shanley's diagnosis; the most eminent of these Being Professor Ivor Browne⁷⁸ who was extremely dismissive of the diagnosis of schizophrenia. Browne's words were a comfort but the damage had been

⁷⁸ Ivor Browne was Professor of Psychiatry at University College, Dublin and Chief Psychiatrist to the Eastern Health Board. In his 'Music and Madness' he writes:

It is my belief that the full picture of schizophrenia is, to a considerable degree, iatrogenic; that is, it is partially created by the psychiatric intervention itself, establishing a pathway of illness behaviour extending over weeks or months, with heavy medication and institutionalisation. Thus, the young person loses connection with ordinary living at a critical time and finds it difficult to reintegrate back into society. It is only then that the full picture of the illness we call schizophrenia supervenes.

Browne, I. (2008). *Music and Madness*. Cork: Atrium, at pp.258-9.

done and welcome though his words were, they did not assuage the sense of diminishment that I carried.

I found it extremely difficult to wean myself off the anti-psychotic medication; the seriousness of the withdrawal symptoms - lack of balance, tremors, and sweats and severe anxiety – was such that it was ten years before I was drug-free. The one positive to be taken from that harrowing experience was that my anger, years later and transformed into energy, enabled me to complete my PhD.

Two themes from that research are of interest here:

- The extremely high levels of misdiagnosis of schizophrenia
- That many Asperger cases were initially diagnosed with schizophrenia;

The extremely high levels of misdiagnosis of schizophrenia

At roughly the same time that I had been given a diagnosis of schizophrenia, David Rosenhan an American academic psychologist who was deeply sceptical of the processes that psychiatrists used in diagnosing schizophrenia, planned an experiment: a number of pseudopatients (the majority being psychologists) sought admission into a variety of mental hospitals by arriving at the admissions office complaining that they had heard voices:

Asked what the voices said, he replied that they were often unclear, but as far as he could tell they said "empty," "hollow," and "thud." ... It is as if the hallucinating person were saying, "My life is empty and hollow."⁷⁹

Immediately on admission the pseudopatients ceased displaying any sign of abnormality; they were told that they would be discharged when they convinced the staff that they were sane. Seeking early discharge, they became model patients but, despite this, their deception remained undetected by the staff. Of the twelve admissions, eleven were diagnosed as schizophrenic and one, "with identical symptomatology" as having manic depressive psychosis.⁸⁰

The study, on publication, caused consternation in the psychiatric profession. Rosenhan arranged a second experiment at a teaching hospital whose staff had heard of the first experiment and who doubted that they could be similarly

⁷⁹ Rosenhan, D. (1973). 'On Being Sane in Insane Places'. *Science*. 179:250-8.

⁸⁰ *Ibid* p.252; this diagnosis (which occurred in the only private hospital in the experiment) was less stigmatising than a diagnosis of schizophrenia.

misled. Rosenhan agreed that he would arrange for a pseudo-patient to seek admission to that hospital within the following three months. Of 193 patients who were actually admitted to the hospital during that period:

*Forty-one patients were alleged, with high confidence, to be pseudopatients by at least one member of the staff. Twenty-three were considered suspect by at least one psychiatrist. Nineteen were suspected by one psychiatrist and one other staff member.*⁸¹

In fact no pseudo-patients had been sent to the hospital and thus the errors of misdiagnosis committed by this hospital were all false negatives – *i.e.* they diagnosed the sick, as healthy.

In my PhD I reviewed the literature in relation to psychiatric misdiagnosis and concluded that that the rate of misdiagnosis of schizophrenia is in excess of 25%⁸².

In view of such high levels, it was unsettling to find it suggested that for an individual diagnosed with schizophrenia to dispute his diagnosis, constitutes a 'denial' which in itself is a further indication of the correctness of the original diagnosis.⁸³

Truly a 'Catch 22' situation and also indicative of the hubris of many psychiatrists who are seemingly unwilling to concede that they are sometimes wrong.

A 2019 study is even more unsettling: at Johns Hopkins Early Psychosis Intervention Clinic researchers reported that about half the people referred to the clinic (having been already diagnosed by other doctors or psychiatrists as schizophrenic) didn't actually have schizophrenia:

Of the 78 patients, 43 (55%) had a primary diagnosis at referral of a schizophrenia spectrum disorder. The primary diagnosis in the consultation clinic was different in 22 (51%) of these 43 cases, and 18

⁸¹ *Ibid.*, p.252.

⁸² Gerry Roche, PhD dissertation, Volume 1, p.185.

Gerry Roche. 'A philosophical investigation into coercive psychiatric practices'. 2 volumes. It is available online at gerryroche.com; academia.edu and criticalpsychiatry.co.uk/

⁸³ Amador, X. & Strauss, D. (1993). 'Poor Insight in Schizophrenia.' *Psychiatric Quarterly* 64(4). 305-318:

"In work with patients with schizophrenia, denial of illness is so common ... that it has become integral to our concept of this disorder."

Amador was co-chair of the final revision of the psychiatric diagnostic manual the DSM-IV-TR (2000) and thus especially authoritative.

(42%) of these patients were not diagnosed with any form of primary psychotic disorder.⁸⁴

In short, the original diagnosis of schizophrenia was incorrect in 51% of cases; thus if the original diagnosis had been made by the simple tossing of a coin, it would have been more accurate!

Even worse, 42% of those diagnosed with schizophrenia by other psychiatrists or doctors, had no psychiatric illness at all. As often occurs in such journal articles, the weasel-word 'overdiagnosis'⁸⁵ is used to refer to such cases in place of what are clearly instances of 'misdiagnosis'.

Asperger cases initially diagnosed with schizophrenia

The *National Autistic Society* notes that the term Asperger derives from a 1944 study by Austrian paediatrician Hans Asperger and that – perhaps because of his involvement with the Nazi euthanasia programme – it lay in abeyance until it was "... introduced to the world by British psychiatrist Lorna Wing in the 1980s"⁸⁶. Thus prior to the 1980's, individuals with Asperger Syndrome would, if subject to a psychiatric diagnosis, have been diagnosed with other psychiatric disorders, most likely with schizophrenia.

In 2002, the director of the Autism Research Unit at Sunderland University, referring to the misdiagnosis of autism as schizophrenia, said:

"There is no doubt that this has been going on for a long time and there may well be some individuals who have been misdiagnosed and treated inappropriately for up to 30 years. These patients are given medication appropriate for schizophrenia, which makes them worse, and they are given more and more medication as a result."⁸⁷

A 2010 study reported that:

A significant number of adults may have an undiagnosed autism spectrum disorder. Some of these will have been managed in mental health services and treated for a psychotic disorder, usually on the evidence of delusional thinking on a background of "negative symptoms."⁸⁸ Although

⁸⁴ Coulter *et al* 'Specialized Consultation for Suspected Recent-onset Schizophrenia: Diagnostic Clarity and the Distorting Impact of Anxiety and Reported Auditory Hallucinations.' *Journal of Psychiatric Practice*. 2019 Mar;25(2):76-81.

⁸⁵ *Ibid* "Clinicians may therefore overdiagnose schizophrenia."

⁸⁶ <https://www.autism.org.uk/about/what-is/asperger.aspx>

⁸⁷ <https://www.scotsman.com/news-2-15012/autistic-adults-locked-up-after-false-diagnosis-1-1359567>

⁸⁸ "... inexpressive faces, blank looks, monotone and monosyllabic speech, few gestures, seeming lack of interest in the world and other people, inability to feel pleasure or act spontaneously."

it is reasonable to believe that a number of these people may indeed have schizotypal disorder (i.e., a disorder nosologically related to schizophrenia), some probably have an autism spectrum disorder without comorbidity and may have therefore been misdiagnosed with schizophrenia.⁸⁹

In 2013, the diagnosis of Asperger Syndrome was removed from the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) and thus it is no longer classified as a psychiatric disorder.

Asperger Syndrome

First an outline of those clusters of behaviours and attitudes that together fall under the rubric 'Asperger'.

MedicineNet lists the following characteristics:

People with Asperger's syndrome have normal to above-average intelligence but typically have difficulties with social skills and often have pervasive, absorbing interests in special topics.

Abnormalities in the subtle use of language and interpretation of language are common with Asperger's syndrome, although language development (grammar, syntax, etc.) is normal.

The degree of severity of symptoms can vary among affected individuals.

Anxiety and frustration may contribute to disruptive behaviors or depression in people with Asperger's syndrome.

The personality and cognitive traits common to those with Asperger's syndrome are seen as beneficial by many, and many people with Asperger's syndrome believe it has helped advance their professional lives.⁹⁰

Professor Michael Fitzgerald of TCD is a renowned authority on autism spectrum disorders; he believes that "There has been a massive broadening and evolution of the concept of autism over the past three-quarters of a century."⁹¹ and that there are continuing difficulties with its definition. He sees a link between Asperger and that particular cast of mind that characterises mathematicians:

In the 'Mind of the Mathematician', internationally famous mathematician Ioan James and accomplished psychiatrist Michael Fitzgerald look at the complex world of mathematics and the mind. Together they explore the behaviour and personality traits that tend to fit the profile of a

<https://www.health.harvard.edu/mental-health/the-negative-symptoms-of-schizophrenia>

⁸⁹ Woodbury-Smith et al 'Autism spectrum disorders, schizophrenia and diagnostic confusion' *Journal Psychiatry Neuroscience*. 2010 Sep; 35(5): 360.

⁹⁰ https://www.medicinenet.com/asperger_syndrome/article.htm

⁹¹ <http://professormichaelfitzgerald.eu/category/aspergers/>

mathematician. They discuss mathematics and the arts, savants, gender and mathematical ability, autism and mathematicians, and the impact of personality disorders and mood disorders. Mathematicians discussed include Gödel, Dirac, Hardy, Hadamard, Kovalevskaya, Poincare, and Gauss.⁹²

His 'Autism and Creativity: Is There a Link Between Autism in Men and Exceptional Ability?' claims that Lewis Carroll, Éamon de Valera, Sir Keith Joseph, Ramanujan, Ludwig Wittgenstein and W.B. Yeats may have been autistic. In 'The Genesis of Artistic Creativity: Asperger's Syndrome and the Arts', he claims that historical figures such as Hans Christian Andersen and George Orwell might have been autistic.

In an *Irish Times* review⁹³ of Fitzgerald's work entitled 'Can Asperger's be an asset?', Kate Holmquist writes:

Seen by many as a disability, Asperger's is also associated with exceptional artistic talent, ...The characteristics of Asperger's, a type of autism, such as the single-minded dedication to a project, amazing memory, social awkwardness and a creative ability to think outside the box, are characteristics we have come to associate with exceptional talent. ... certain autistic tendencies - such as the ability to focus ruthlessly - can be an advantage in making great art ...

She quotes Fitzgerald:

"Persons with the syndrome are often workaholics, highly persistent, content with their own company and solitary artistic occupations; they focus on detail with massive curiosity and total immersion; they are novelty-seekers in terms of their art, with massive imagination in their specialised spheres. They are also far less influenced by previous or contemporary artists in their work than are 'neurotypicals'

In the words of Greta Thunberg:

"For those of us who are on the spectrum, almost everything is black or white. We aren't very good at lying, and we usually don't enjoy participating in this social game that the rest of you seem so fond of,..."⁹⁴

I read those lists of Asperger characteristics with that same sense of recognition as when one catches a glimpse of one's face in a mirror. Briefly I thought of seeking a psychiatric re-diagnosis but quickly rejected it on the

⁹² *Ibid.*

⁹³ <https://www.irishtimes.com/news/health/can-asperger-s-be-an-asset-1.475517>

⁹⁴ <https://www.insider.com/greta-thunberg-9-times-climate-change-activist-left-us-speechless-2019-5#she-only-takes-the-train-when-she-travels-around-europe-for-her-climate-action-movement-3>

basis of *'once bitten twice shy'*. Those characteristics of innovativeness, introversion, creativity, ploughing my own path with stubbornness, were the gifts that enabled me to complete my PhD, various building and craft projects – even building a log-cabin – and much else ...

I wish to finish this discussion with some remarks by Simon Baron-Cohen who is the leading UK authority on Asperger Syndrome.⁹⁵ He argues persuasively⁹⁶ that rather than the term *'disability,'* the term *'difference'* should be used in relation to Asperger Syndrome as being a more neutral, value-free, and fair description.

He notes that a child with Asperger Syndrome *"...is often described as holding forth like a 'little professor' on his or her favorite subject."*⁹⁷ Such a child *"... notices and recalls things other people may not"* and is often *"... immersed in the world of things rather than people."*

In emphasising the *'gifts'* that autism may confer he mentions two anecdotes: whilst attending a conference autism in Toronto, one contributor asked:

*"What would happen if you eliminated the autism genes from the gene pool? You would have a bunch of people standing around in a cave, chatting and socializing and not getting anything done!"*⁹⁸

Which, he says, nicely illustrates that the genes for autism may lead to a different cognitive style that has enormous practical value in its own right.

*"A research assistant with Asperger syndrome working at Yale gave me another anecdote. He said, "If we are autists, you guys are heterists. The diagnostic features of heterists are making lots of eye contact, and overlooking details such as small coins on patterned carpets or car number plates." To him, this anecdote emphasizes our differences, and raises the question in an amusing way about why one style should be regarded as a disability."*⁹⁹

As I read Baron-Cohen's article I saw some of the shame and hurt that I had been carrying for close to fifty years float away and my full human dignity return – not *'flawed'*, not *'damaged'* not *'diagnosed'* but just different –

⁹⁵ He is professor of developmental psychopathology at the University of Cambridge; the Director of the University's Autism Research Centre and a Fellow of Trinity College

⁹⁶ In his paper *'Is Asperger Syndrome Necessarily Viewed as a Disability?'* online at: http://docs.autismresearchcentre.com/papers/2002_BC_ASDisability.pdf

⁹⁷ As a teenager that is how my young sister Mary (now sadly deceased) would describe me!

⁹⁸ *Op cit.*

⁹⁹ *Op cit.*

wonderfully and thankfully different and finally free from the casuistry and 'labelling' of the psychiatrists.

With luck I fly to Samarkand in 10 days time but now for the first time pain, an all-encompassing pain, has made its appearance; before, it was just discomfort. Having made its introduction the severe pain lasted but a day; doubtlessly it will be back but there is no virtue in worrying about that. Recently I visited a dentist for a check-up which I had long postponed; a molar was badly infected but it had been so on an earlier x-ray of three years earlier and the infection hadn't progressed. He was loath to remove the tooth because the infection could easily spread and, in my present weakened position, I might have difficulty in combating it. He gave me some antibiotics least the infection flare up whilst I was travelling.

Now the task of packing my rucksack but I have the feeling that heading to Uzbekistan is pushing the boat so far out that it is no longer supported by water but by its own momentum, blind faith and stubbornness.

Dare I write "... *to be continued!*" – or does this tempt fate?

"... *to be continued?...*"

21st September 2019

The journey back to Clare had been difficult: the flight from Samarkand to Istanbul took 5 hours, then a four hour wait at the airport then a five hour flight back to Dublin. The four hour time difference meant that other than catnaps on the plane, I didn't sleep for over 24 hours.

I had booked (free!) a wheelchair in Istanbul which was a magnificent help as the new airport, though superb architecturally, is huge. An old friend very kindly drove me down to Clare the following day.

Whilst I was away, the weather in Ireland had been bleak but arriving home again I was suddenly blessed with some days of glorious sunshine. One such was the day before the Autumn Equinox when the weather was superb with clear blue skies, and I sat out and watched the sun go down just slightly to the

right¹⁰⁰ of a mountain cairn which I had built some thirty years ago with my then ten year old son, Philip, to mark the position of the sunset at the equinox. The following day – the equinox - all was shrouded in a deep grey mist.

I live on a north facing coast in Clare and, to the south, I am surrounded by the hills of the Burren behind which the sun lurks, hidden, in the darkest days of winter hence I have become acutely conscious of the presence – or, more accurately, the absence - of the sun. The idea of constructing a cairn was to create a sundial of the seasons rather than of the hours; in midsummer the sun sets over Twelve Bens in Connemara; some two weeks later as it sets, it appears to roll down the Burren hillside to the sea at Black Head. With a cairn to mark the equinox, I have the mountains as my own very own calendar. Positioning the cairn in the days before mobile phones, first necessitated that, at the equinox, I took a compass reading of the sunset from my house; later, Philip headed up the mountain and having worked out a system of signalling using coloured flags (green to go left, red to go back ...) Philip built the cairn to coincide with the position indicated by me according to the earlier compass bearing. It gave me enormous pleasure to sit and watch the sun set alongside the cairn – a feeling of continuity and utter connectedness with nature!

The weather in Samarkand was superb, the temperature was just under 30deg and clear blue skies. Occasionally a cloud might appear on a distant horizon but it was like a lone gatecrasher at a party whom you know will soon be evicted and peace again restored to the land.

The city is one of the oldest in the world, the old town is now surrounded by a Russian-built modern metropolis with wide tree-lined streets, flower-beds and parks. Watching the people here made me reflect on how when compared with a modern western city and whilst the Uzbeks may be less affluent, they appear to have a socially richer society in that they have the time to leisurely stroll about the city with a degree of unhurriedness unimaginable in the West. The women dress with such a sense of style, colour and elegance that should be the envy of many westerners whilst their children play in the parks with a degree of freedom and inhibition that would now be rarely seen in the west.

¹⁰⁰ Slightly to the right? - it was, after all, a day early!

Having just come to the above conclusion and whilst waiting for service in a local restaurant, a young woman entered and physically assaulted a young waitress. After much hair pulling, scratching and screaming she was evicted - a 'MeToo' on 'MeToo' moment which made me question my rose-tinted view of a society of which I have but the scantiest knowledge.

The old city is close to 3000 years old and reinforces the belief that the birth of civilisation was here in the East and that Western bravado and arrogance is very much a latecomer to the party. It is so beautiful that whilst I would rarely take photos whilst travelling, this time I decided to take absolutely none and what surprised me was the incredible sense of unconstrained liberty that that gave me: before, in seeing something of extraordinary beauty one puzzled as to how best one might capture it in a photo: from here in full sunlight or there? Which better captures some telling detail? Inevitably the photo could not do justice to what was seen and whole procedure of taking a photo meant that one couldn't appreciate what was in front of one's eyes. Without a camera one knows that now is the only chance to fully see and one should open ones eyes as fully as possible to drink in all as this will be the only opportunity to ever do so.

Islamic mosques whilst often having a complex surface geometrical decoration of tile-work and flowing calligraphy, these never hinder the architectural simplicity of the construction which stand in such deep contrast with the confections of, for example, Spanish Catholic churches with their plethora of pictures and statues and clutter. The writer Robert Byron, in contrasting Istanbul's St. Sofia with the Vatican, describes it: "*The existence of St. Sophia is atmospheric; that of St Peter's, overpowering, imminently substantial. One is a church to God; the other a salon for his agents.*"

My own contrast would be St. Sophia and Galway Cathedral which in its brute size and ugliness, is a monument to overweening clerical claims to power; the only building that I have seen that evokes a similar feeling is that of the Potala Palace in Lhasa. The Potala Palace is built on an elevated site and its frontage is tilted back from the vertical so that it looks beyond and never sees the crowds of supplicants at its feet. Much like the Catholic Church in England it was only with its loss of temporal power that Tibetan Buddhism regained

something of the humility and spirituality that should be the hallmark of any religious endeavour.

I had originally planned to travel to Bukhara by train but soon realised that I no longer had the strength to manipulate my rucksack from a taxi to the train and then to the hotel in Bukhara. I was becoming weaker by the day.

Moreover a 1-person taxi for the 280km journey cost but €40 so the decision was clear. On leaving the city boundary, the taxi driver – doubtlessly seeking a blessing on our trip - drew his hands over his eyes and paused with open palms; this of course necessitated that he take his hands from the steering wheel whilst his eyes remained closed; I would have had a little more faith in his eyes than in his prayers!

Bukhara had been one of the holiest places in Islam but coming here it was difficult to discern any sense of spirituality; utterly different from the mosques in Aleppo or Isfahan or even Samarkand; the mosques in the main were full of stalls selling craft goods which were of excellent quality but I was amazed at the number of Europeans here, Germans, French and even Norwegians particularly as I had thought of Bukhara as being difficult of access.

Wondering, I searched online for "*Cheap flights Europe to Bukhara*" and found a web link¹⁰¹ based on a €90 return flight from Budapest to Kazakhstan and connecting buses from such as Oslo to Budapest and, on the other end, from Kazakhstan to Bukhara all in for €360 ; that and similar offers explain the crowds because Bukhara is a little like a Marrakesh for oldies - a great pity but, in this, I fully note my own hypocrisy, arrogance and presumption!

The Bukhara hotel that I had booked was small and no English was spoken (this was the hotel which I mentioned earlier, that replied to me in Gaelic)! All communication was on a smartphone using Google to translate spoken Uzbek to English text.

In booking the hotel I had asked as to whether the rooms were easy of access and had been assured that they were but on arrival I saw that all rooms were upstairs and the steps steep. Mounting the steps was not a problem but descending involved keeping one foot on the upper step and seeking gingerly

¹⁰¹<https://www.fly4free.com/flight-deals/europe/spring-trip-to-central-asia-astana-tashkent-bukhara-samarkand-bishkek-and-almaty-in-one-trip-from-budapest-for-e354/#more-390996>

with my other foot for the lower step and even with my now ever-present walking stick, this was a hazardous operation - I had to launch myself forward making a leap of faith something of which I have not had much practice! Much like Oscar Wilde dying in his Paris hotel room declared: "*This wallpaper and I are fighting a duel to the death. Either it goes or I do*"; I felt that unless I changed hotels those stairs would be the death of me. Miraculously - like the prophet Daniel - a dream in the night saved me: I could descend the stairs backwards!

One morning as I headed down to breakfast - with my Google smartphone photo of two fried eggs - the cook approached, smiling, and proffering her own smartphone, offered me a delicacy *via* Google translate: "*Would you like three fried testicles?*". Not yielding to my curiosity as to whose they might be, I graciously declined!

A couple of days earlier I had had a stomach bug and the owner's wife had kindly brought me a meal which I did not feel up to eating. She insisted, so I took just the soup which was good and nourishing; in it were potatoes and a carcass of a small bird the size of a lark and three grey meat-like spheres - it didn't cross my mind as to what they might be and I just drank the soup and next morning I was fine but, in future, 'soup' will no longer echo the innocence of an Irish childhood, now it will be carefully scrutinised and with great suspicion!

My last evening in Bukhara, a seemingly innocuous, seemingly trivial incident occurred; a thing of no consequence yet it has stayed with me: I had been sitting in a small park just watching the tourists, the locals and the children playing. I was heading back to my hotel and to avoid the steps up from the park, I was using an adjacent wheelchair ramp. I had used it before and found it steep but a handrail allowed me to drag myself up it.

A labourer pushing a wheelbarrow full of hedge clippings, was approaching the ramp so I let him go first, me following behind. As he approached the top of the ramp, he stalled and began to slip backwards, I pushed him from behind and he recovered. Meanwhile I myself was stuck when suddenly the hand of a young Chinese helped me forward. We had no common language but the

mutual smiles were pregnant with a meaning transcending any need for language.

On my return to Samarkand, of the many mosques and mausoleums that I had seen on my first visit, there was just one that I was most anxious to see again: the Gur-e-Amir mausoleum – although one of the smallest, it was to me undoubtedly the most beautiful and spiritual of the buildings that I had seen and also the most evocative of the grandeur and intellectual splendour of the empire ruled by Timur (or Tamerlane –(Pr.) '*Timur the Lame*': 1336 – 1405). He had founded the Timurid Empire which extended from Istanbul in the West to the Caucasus and southern Russia with sallies as far as Moscow, in the North; to Syria, Iran, Iraq in the South and to Afghanistan and Pakistan in the East. He died as he was beginning a campaign to subjugate the Ming Dynasty in China.

He was the grandfather of the Timurid sultan, astronomer and mathematician Ulugh Beg, and an ancestor of Babur (1483–1530), founder of the Mughal Empire which then ruled almost all of the Indian subcontinent. It was in the Taj Mahal in Agra that the architectural style manifested in the Gur-e-Amir reached its fullest flowering.

Timur's spiritual mentor was the Sufi saint Sayyid Baraka who is buried alongside Timur and his memorial gravestone is something at once both shocking in its apparent incongruity and, in this, eloquent in its tribute: it is a 6 meter vertical stem or trunk of what may have been a poplar tree, devoid of bark and branches save one 18" horizontal branch close to the top. From this hangs what I have been told is a pomegranate wrapped in the hair of a horse's tail. As to its religious significance, despite numerous enquiries I remain ignorant but viewed as a piece of art, set against such a formal background, it is stunning – so much so that I came again on a third visit just to gaze and wonder – mesmerised!

In travelling to Samarkand I brought some books with me – companions for my journey - one such was *'Leo the African'* by Amin Maalouf¹⁰² which tells the story of the Muslim world through the eyes of a youth forced by the Inquisition to leave Islamic Spain. Earlier in these pages, I have discussed the *'denial of death'* and idea of *'a good death'* and there is a passage in Maalouf's book far more eloquent than anything that I could write and which is worth quoting:

Too often, at funerals, I hear men and women believers cursing death. But death is a gift from the Most High, and one cannot curse that which comes from Him. Does the word "gift" seem incongruous to you? It is nevertheless the absolute truth. If death was not inevitable, man would have wasted his whole life attempting to avoid it. He would have risked nothing, attempted nothing, undertaken nothing, invented nothing, built nothing. Life would have been a perpetual convalescence. Yes my brothers, let us thank God for having made us this gift of death, so that life is to have meaning; of night, that day is to have meaning; silence, that speech is to have meaning; illness, that health is to have meaning; war, that peace is to have meaning. Let us give thanks to him for having given us weariness and pain, so that rest and joy are to have meaning. Let us give thanks to Him, Whose wisdom is infinite.¹⁰³

As a student, I once attended a reading of excerpts from Joyce's *Finnegans Wake*,¹⁰⁴ in a small theatre located in the basement of what was then the British Embassy in Merrion Square, an embassy which was subsequently burned down in protest against the Bloody Sunday killings in Derry.

The beauty of the final lines of *Finnegans Wake*, shocked me, pained me much as Rilke has described the pain caused by experiencing extreme beauty: "... *for beauty is just the beginning of terror, which we are barely able to endure*"¹⁰⁵

Though I have never read the book in its entirety, I sometimes dipped into it and always back to those last lines which brought to mind firstly the memory of my own father bringing me as a young child, on his shoulders around a local carnival in Drumcondra close to where we lived but even more importantly, for

¹⁰² Earlier I had read his *'Samarkand'* - a novel set in 11th century Persia, about the poet and philosopher Omar Khayyam.

¹⁰³ Maalouf, Amin. *'Leo the African'*. London. Abacus. 1994, p.103.

This quotation is reminiscent of the Tao:

*Under Heaven all can see beauty as beauty only because there is ugliness.
All can know good as good only because there is evil.*

Lao Tzu *'Tao Te Ching'* Chapter 2 (translation by Gia-fu Feng and Jane English)

¹⁰⁴ London: Faber & Faber (1966)

¹⁰⁵ Rainer Maria Rilke *'The Duino Elegies'*.

its wonderful image of death as a return to the source about which little else can be said other than it is the forge from which will be created all future generations¹⁰⁶:

I am passing out. O bitter ending! I'll slip away before they're up. They'll never see. Nor know. Nor miss me. And it's old and old it's sad and old it's sad and weary I go back to you, my cold father, my cold mad father, my cold mad feary father, till the near sight of the mere size of him, the moyles and moyles of it, moananoaning, makes me seasilt saltsick and I rush, my only, into your arms. I see them rising! Save me from those therrble prongs! Two more. Onetwo moremens more. So. Avelaval. My leaves have drifted from me. All. But one clings still. I'll bear it on me. To remind me of. Lff! So soft this morning, ours. Yes. Carry me along, taddy, like you done through the toy fair! If I seen him bearing down on me now under whitespread wings like he'd come from Arkangels, I sink I'd die down over his feet, humbly dumbly, only to washup. Yes, tid. There's where. First. We pass through grass behush the bush to. Whish! A gull. Gulls. Far calls. Coming, far! End here. Us then. Finn, again! Take. Bussoftlhee, mememormee! Till thousandsthee. Lps. The keys to. Given! A way a lone a last a loved along the

My strength is ebbing, my memory and sight are deteriorating; indeed once in Samarkand whilst relaxed and sitting peacefully, I suddenly had a double-vision; this lasted but a few moments, but I have no desire to have it 'investigated'. My rucksack, like me, has had its final voyage.

At night sometimes I feel the beginnings of an all-over skeletal pain but I have been assured that when I require it, pain medication will be readily available. This is the only medical intervention that I require.

My death is coming down the line, how fast or slow I do not know but sometimes when my breathing is laboured and energy low it seems like days and then things lighten and change; to try and seek medical opinion on how

¹⁰⁶ Standing on the quay, I was often intrigued in watching a shoal of small fish swimming below and when dropping a pebble amongst them, seeing them scatter but then quickly regroup. To me, it seemed that these fish could move with ease between an individual, and a collective, consciousness.

People are often fixated on their individual consciousness often indeed denying the existence of any collective consciousness. Over the years I have carried with me as an image of the collective unconsciousness, that of a tree with individuals being simply the tendrils or individual roots, their 'task' being to overcome whatever obstacles they find in their way; unknownst to them all that they learn – their apparent 'successes' or 'failures' – are fed back to that great source 'tree' to inform future generations.

long is left would be of no use to me and on that I have absolutely no doubt because it would unsettle any degree of composure that I now have. For me to try and sit in the acceptance that my death is reasonably immanent and not lose my mental calm is crucial. It is as if I have found a centre of gravity where I can rest and any attempt at medical intervention, would lead to an overreach and a loss of that centring.

Over the last months, my writing these notes has helped but it no longer does and I do not believe that I have anything useful to add, so to finish:

"A way a lone a last a loved along the "

1st October 2019